The Experience of Active Injection Drug Use on Adherence to Antiretroviral Treatment in Aboriginal

People Living in Prince George – A Qualitative Perspective

By

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Abstract

In Canada the incidence rates of HIV in Aboriginal populations continue to grow. Reasons for the increased Aboriginal HIV incidence are varied including structural components such as socio-economic issues, and limited access to healthcare. The purpose of this study is to gain insight into how active injection drug use impacts adherence to antiretroviral treatment in Aboriginal people living in Prince George, British Columbia. Analysis revealed that healthcare providers need to me more *caring* and *consistent* in their approach. Adherence is facilitated by the knowledge of the health *consequences of non-adherence*; *trust* in healthcare providers; incorporating HAART into daily *routines*; receiving *support* from AIDS services organizations, and that combining HAART administration with *methadone* is an effective pathway to increase adherence. The most common barrier to adherence identified by the participants was "*being high*". Finally the study found that the majority of participants expressed a feeling of disconnection from Aboriginal culture.

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Chapter 1: Introduction

Rationale for Research Project

In the early years of the HIV/AIDS^{1,2} epidemic in Canada, authors and decisions makers raised the concern that HIV/AIDS would become the leading cause of death for Aboriginal³ Canadians in the near future. In Canada, the incidence rate for HIV has decreased in the general population, but has increased steadily in Canadian Aboriginal populations (Health Canada, 2006). Data shows that from 1985-1997, 15% of positive HIV tests were among Aboriginal Canadians (Public Health Agency of Canada, 2007). In 2007, this number jumped to 21.4% (Public Health Agency of Canada, 2007). Reasons for the increased rate of HIV infection in Aboriginal people are varied, and include socio-economic issues, poverty, addiction and limited access to healthcare all of which have been perpetuated by a history of colonization and marginalization (Health Canada, 2006; Newbold, 1998). With this context in mind, it is not surprising that the difficulties of managing HIV - a disease which involves complex treatment regimens, high levels of adherence for success, and wide variations in health status - can create unbearable burdens on the people infected. These burdens can ultimately result in the person living with HIV failing to engage in and maintain care, or the eventual disengagement of HIV related healthcare altogether. For these reasons, it is imperative that greater efforts be made to understand the realities faced by Aboriginal people in accepting, engaging in, and sustaining HIV medication adherence. This

¹ HIV stands for Human Immunodeficiency Virus, it is a virus that attacks the immune system, resulting in a chronic, degenerative illness that eventually renders the immune system helpless against invading pathogens HIV is the precursor infection to the development of AIDS (Public Health Agency of Canada, 2009)

² AIDS stands for Acquired Immuno-Deficiency Syndiome In Canada, an official diagnosis of AIDS is made when a person living with HIV develops one or more opportunistic infections or certain cancers (Canadian AIDS Treatment Exchange, 2006)

 $^{^{3}}$ The term "Aboriginal" refers to the descendents of the original inhabitants of Canada, namely, the First Nations (61%), the Metis (34%) and the Inuit (5%), who are three distinctly different groups, all with unique geographic and linguistic heritages, cultural practices and spiritual beliefs (Macaulay, 2009)

research project will focus on one realm of hardship – addiction – and its role in the adherence of Aboriginal people trying to succeed on Highly Active Antiretroviral Therapy (HAART)⁴.

My reasons for doing this research come from his time spent in the Downtown Eastside of Vancouver, British Columbia, working at Insite⁵ and the Vancouver Injection Drug User Study (VIDUS).⁶ In this time, I learnt that a recognizable percentage of the clients at Insite and research participants at VIDUS were actually Aboriginal people from Northern British Columbia. These Aboriginal people reported a high migration rate to and from Northern British Columbia and a lack of accessible healthcare and harm reduction services. I am from Northern British Columbia, and I have developed a great interest and empathy in hearing the stories of injection drug use among my fellow northern residents of British Columbia. When I decided I wanted to return to school for my graduate education, I knew that I wanted to study HIV, and injection drug use in Northern British Columbia. It took very little research to learn that HIV is a disease that is ravishing the Aboriginal people of Northern British Columbia. From this knowledge, I knew who, what and where I wanted to study for my thesis.

⁴ HAART is the medication regime used to suppress HIV viral replication and slow the progression of HIV disease. HARRT combines three or more different drug classes such as two nucleoside reverse transcriptase inhibitors (NRTIs) and a protease inhibitor (PI), or two NRTIs and a non-nucleoside reverse transcriptase inhibitor (NNRTI), or other such combinations (Cichocki, 2009)

⁵ Insite is North America's first legal supervised injection site – Insite operates on a harm-reduction model, which is a policy or program directed towards decreasing the adverse health, social and economic consequences of drug use without requiring abstinence from drug use http://supervisedinjection.vch.ca/

⁶ The Vancouver Injection Drug Users Study (VIDUS) is a cohort study in Vancouver's Down-town Eastside VIDUS follows approximately 1500 participants. Every six months, VIDUS participants provide blood samples to be tested for HIV and hepatitis C, and they are interviewed about their drug use patterns and practices, health status, access to health and social services, and interactions with the criminal justice system. http://uhii.cfenet.ubc.ca/content/view/35/57/

Chapter Two: Review of Literature

Introduction

In this chapter, the academic literature relating to HIV, injection drug use, and Aboriginal people will be explored. The literature review is presented in six broad segments. The first segment gives a brief but ample overview of the global epidemiology of HIV. It then presents HIV epidemiology within the Aboriginal populations of Canada, British Columbia, and Northern British Columbia. The second segment provides a comprehensive overview of HIV treatment – highly active antiretroviral therapy (HAART), and a short discussion around the usage of HAART among British Columbia Aboriginal people. Thirdly, adherence to HAART is discussed with a focus on three groups: people who use injection drugs, Aboriginal people, and Aboriginal people who use injection drugs. Next, this section will explore the barriers to accessing healthcare among Aboriginal people from a social justice perspective and a culturally safe care perspective. Lastly, the gap in literature is discussed pertaining to the lack of knowledge regarding Aboriginal people who use injection drugs and who are on HAART.

Information for this literature review was obtained from searches that consisted of keyword⁷ searches in various electronic databases including Medline, EBSCOhost, Science Direct, Web of Science, Elsevier Heath, and various electronic journals such as Journal of Association of Nurses in AIDS Care, Journal of the American Medical Association, AIDS, American Journal of Drug & Alcohol Abuse, Social Science & Medicine, Journal of Acquired Immune Deficiency Syndrome, Drug and Alcohol Dependence and the International Journal of STD and AIDS. These searches attempted to locate literature that explored the demographics of HIV within selected Canadian and Canadian Aboriginal populations, barriers to HAART

⁷Keywords used in the literature search were adherence, illicit drugs, abuse, injection drug use, drug users, HIV/AIDS, antiretrovital therapy, treatment, non-adherence, medication adherence, HARRT, Aboriginal, Indigenous and qualitative research

adherence for people who use injection drugs, barriers, Aboriginal people, and general information about HAART.

Literature Review

Global Epidemiology of HIV. Globally, the prevalence of HIV is levelling off, and the number of new infections worldwide has fallen (World Health Organization, 2007). The World Health Organization (WHO) estimates the number of people living with HIV in 2007 was 33.2 million, with 2.5 million people newly infected, and 2.1 million deaths of AIDS-related complications (WHO). The WHO estimates that daily, there are 6,800 new HIV infections, and over 5,700 deaths from AIDS worldwide (2007). It is estimated that injection drug use is the route of transmission for approximately 10 percent of new HIV infections in the world (Spire, Lucas, & Carrieri, 2007).

Canadian Epidemiology of HIV. In terms of HIV, the World Health Organization approximates that there are 73,000 people living with HIV in Canada, with an adult prevalence of 0.4 percent, and an annual mortality rate of less than 500 deaths (2008).

Demographics and HIV Epidemiology of Canada's Aboriginal People. In 2006, Aboriginal Canadians represented 3.8% of the total Canadian population. This was an increase from 3.3% in 2001, and 2.8% in 1996 – in fact, the Aboriginal Canadian population grew at a rate six times faster than the non-Aboriginal population from 1996-2006 (Statistics Canada, 2006). In 2001, 41% of Aboriginal children under the age of fourteen were living in poverty, a rate three times higher than the national average (Macaulay, 2009). Additionally, in 2006, 11% of Aboriginal people were living in overcrowded conditions, a rate four times higher than the national average (Macaulay, 2009). In 2005, Aboriginal people represented approximately 9% of new HIV infections in Canada, and represented approximately 7.5% of all persons living with HIV in Canada (Boulos, Yan, Schanzer, Remis & Archibald, 2005). In relation to injection drug use, surveillance reports that include ethnicity indicate that injection drug use accounted for 40% of reported AIDS cases associated with Aboriginal people from 1979 to 2006, and 60% of HIV positive tests in Aboriginal people from 1998 to 2009 (Public Health Agency of Canada, 2007b; Public Health Agency of Canada, 2009). Figure 1 breaks down the exposure categories based on ethnic status, it clearly illustrates that Aboriginal people are over-represented in the injection drug use exposure category when compared to other ethnicities living in Canada.



Figure 1: Proportion of positive HIV test reports, by ethnic status and exposure category, 1998-2009 (Public Health Agency, 2009).

In terms of being diagnosed with AIDS, Aboriginal people comprised 24.4% of reported AIDS cases that contained ethnicity in 2006 (Public Health Agency of Canada, 2007a). Summative data from 1999-2009 show that Aboriginal people accounted for approximately 12% of all AIDS diagnoses in Canada (Public Health Agency of Canada, 2009). A note of concern can be seen in the fact that an analysis of reported cases of AIDS from 1996 to 2005 found that Aboriginal people were significantly more likely to have a late diagnosis of HIV as compared to non-Aboriginal AIDS cases (Mill, Jackson, Worthington, Archibald, Wong, Myers, Prentice & Sommerfeldt, 2008). In addition, figure 2 shows that Aboriginal people are increasingly represented in the reported AIDS cases from 1979-2009.



Figure 2: Proportion of reported AIDS cases by ethnicity (Public Health Agency, 2009).

Provincially, in 2006 Aboriginal people accounted for approximately 5.1% (196,075) of the 3,878,310 people living in British Columbia (British Columbia Stats, 2006). From 1995 through the year 2000, 19% of the new HIV infections and 14% of the AIDS diagnoses were among Aboriginal people (Miller, Spittal, Wood, Chan, Schechter, et al., 2006). From 2001 to 2007, the HIV infection rates in Aboriginal people in British Columbia remained relatively stable, with the average total number of infections being 62 per year, totalling 15.2% (433) of the total number of new HIV infections in BC (British Columbia Centre for Disease Control, 2007). The British Columbia Center for Disease Control (BCCDC) reported that in 2007, there were 395 new HIV positive cases, of which, 13.4% (53) identified as being Aboriginal (BCCDC). In examining the rates of death due to AIDS in British Columbia, Status⁸ Indians have seen their known rates double from 0.8 per 10,000 in 1993 to 1.9 per 10,000 in 2006 (Office the Provincial Health Officer, 2009). Furthermore, a study by Miller et al. (2006) found that Aboriginal people in British Columbia were less likely to have a physician experienced in treating HIV.

In the Northern Health Region,⁹ the region that is the focus of this research project, Aboriginal people account for approximately 20% (65,000-85,000) of the total population (Northern Health, 2008a). The HIV incidence amongst all people is 18 per 100,000 – the second highest of any community studied in British Columbia (Northern Health, 2008). From 1998-2007 the Northern Health Region had 177 new HIV infections, and of these, Aboriginal people accounted for 60.45% (107) of the total number (Northern Health, 2008). In 2007, Aboriginal people accounted for 58% of the new HIV infections in the Northern Health Authority, compared to 15% of the total infections for all of British Columbia (Northern Health, 2008).

⁸ "Status" is a term used by the federal government that recognizes Aboriginal persons registered under the *Indian Act* Status Indians are entitled to a wide range of programs and services offered by federal agencies, provincial governments and the private sector Historically, entitlement to Indian status and Indian band membership has been complex and controversial (Indian and Northern Affairs Canada, 2009)

⁹ The Northern Health Region – also known as the Northern Health Authority – covers almost two-thirds of British Columbia's landscape, bordered by the Northwest and Yukon Territories to the north, the BC interior to the south, Alberta to the east, and Alaska and the Pacific Ocean to the west. The Northern Health Region is divided into three operational areas called Health Service Delivery Arcas (HSDAs) the Northeast, the Northern Interior, and the Northwest. In 2010 approximately 348,000 people will live in Northern BC, with 13% of the population identifying as Aboriginal, the highest proportion in the province (Northern Health, 2009b).

Highly Active Antiretroviral Therapy. The gold standard treatment for HIV/AIDS is a combination of medicines called Highly Active Antiretroviral Therapy (HAART; Canadian AIDS Treatment Information Exchange (CATIE), 2006). There are two main classes of HIV medications that are included in HAART for patients who are treatment naive: reverse transcriptase inhibitors – which include both Nucleoside Reverse Transcriptase Inhibitors (NRTIs) and Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTIs) – and protease inhibitors (PIs; CATIE, 2006). HAART is the combination of at least three or more drugs from these two classes (CATIE, 2006), as the use of only one drug was found to have a high predisposition to developing resistance in the early days of HIV treatment (Avert, 2009). Each medication works by disrupting the actions of different proteins that HIV needs to reproduce (CATIE, 2006). HAART is among the most complex treatment regimens ever prescribed, typically requiring anywhere from one pill once a day, to 10-20 pills per day at various times, with strict coordination with meals (CATIE, 2006; Weiss, 1999). The complexity of HAART treatment is increased by the fact that greater than 95% adherence is needed to achieve high levels of virological and immunological response (Lima, Harrigan, Murray, Moore, Wood, et al., 2008). If the required high levels of adherence are not maintained, the development of drugresistant strains of HIV may occur. This can cause a return to the high levels of HIV viral load, often seen in people living with HIV prior to commencing HAART (Weiss, 1999).

In British Columbia, only 50% of people who are living with HIV and who are eligible¹⁰ for HAART receive it (Office of the Provincial Health Officer, 2007). Reasons cited for the low levels of HAART uptake are that many people who are eligible for treatment are in "hard-to-

¹⁰ According to the BC Center for Excellence in HIV/AIDS, HARRT should be started for "asymptomatic individuals before the CD4+ count falls below 500 cells/ μ L. At present, there are no definitive randomized clinical trial data to define a specific CD4+ count threshold above 500/ μ L for beginning therapy. Therefore in this group, decisions should be based on co-moibidities, risk for disease progression (including lisk for non-AIDS diseases), and patient willingness to adhere to long-term treatment." (British Columbia Centre for Excellence in HIV/AIDS, 2009, p.6)

reach populations" – i.e. people who are addicted to drugs, have mental illnesses, are homeless, and/or are living in remote locations – all conditions or situations that Aboriginal people are disproportionately represented in (Office of the Provincial Health Officer, 2009). A recent study reported that Aboriginal persons accessing HAART had shorter survival and mortality rates that were three times higher than non-Aboriginal Canadians due to a combination of late diagnosis of HIV, and late initiation of HAART (Lima, Kretz, Palepu, Bonner, Kerr & Moore, 2006). In fact, a study by Wood and colleagues (2003a) found that since the introduction of HAART in British Columbia, one-third of people who have died from AIDS-related complications had never received antiretroviral therapy, and that Aboriginal ancestry was associated with dying without receiving treatment for HIV/AIDS. Additionally, Aboriginal people receiving HAART in British Columbia were more likely to be living below the poverty line and in unstable housing than non-Aboriginal people (Miller et al., 2006).

Adherence to HAART. A review of the existing literature unequivocally demonstrates that high levels of adherence – over 95% – are needed for HARRT to achieve maximum viral suppression, reduce mortality and morbidity, and increase the quality of life for persons living with HIV (Garcia, & Cote, 2003; Russell, Krantz & Neville, 2004; Stein, Rich, Maksad, Chen, Hu, Sobota & Clarke, 2000; Ware, Wyatt & Tugenberg, 2005; Wood, Montaner, Tyndall, Schechter, O'Shaughnessy & Hogg, 2003b). In fact, HIV disease progression and deaths attributed to AIDS among people receiving antiretroviral therapy in many parts of the world is so rare, that HIV is now recognized as a chronic and manageable illness (Wood et al., 2003b).

The difficulties of achieving high levels of adherence are well documented in the literature (Ware et al., 2005; Russell et al., 2004; Stein et al., 2000). Reasons for the difficulties in achieving high adherence include, but are not limited to, the complexity of the medication

regimens, the severity of side effects, forgetfulness of the patient, mental health issues, residential patterns, stigma, lack of knowledge of HIV and disease process, inadequate coping mechanisms, dietary recommendations, disruption to daily routine, physical factors, required life-long therapy and addiction issues (Garcia & Cote, 2003; Gray, 2006; McDonnell, Pace, Anindya & Ura, 2006; Sorensen, Haug, Delucchi, Gruber, Kletter, et al., 2007; Stein et al., 2000; Ware et al., 2005). In addition, many people living with HIV are marginalized – for example, many Aboriginal people and people who use injection drugs – and such populations frequently distrust health providers (Mallinson et al., 2007). In 2006, a study by McDonnell and colleagues found that high levels of adherence to HAART was significantly correlated with fewer years living with HIV, fewer years on HAART, high levels of perceived support, absence of perceived barriers, high levels of self-identified general health, a dedicated intention to adhere to the medication regimen, and a strong belief in the effectiveness of the medications.

HAART Adherence in People Who Use Injection Drugs. The overwhelming theme in existing research literature is that people who are living with HIV and active addiction have great difficulty achieving high levels of adherence to HAART (Arnsten, Demas, Grant, Gourevitch, Farzadegan, et al., 2002; Cofrancesco et al., 2008; Gordillo, Amo, Soriano & Gonzalalez-Lahoz, 1999; Lert & Kazatchkine, 2007; Lucas, 2001; Sorensen et al., 2007; Spire, Lucas & Carrieri, 2007; Ware et al., 2005; Stein et al., 2000; Wood et al., 2003a). A study on the determinants of discontinuation of HAART in Vancouver, British Columbia found that up to 50% of people who use injection drugs discontinue therapy prematurely, and that among the 50% remaining on treatment, 60% of them have suboptimal adherence to HAART (Kerr, Marshall, Walsh, Palepu, Tyndall & Montaner, 2005; Kerr, Palepu, Barnes, Walsh, Hogg & Montaner, 2004). To further this point, Wood and colleagues (2003b) found that suboptimal adherence in people who use injection drugs leads to a more rapid HIV disease progression due to lower virological response to treatment. In the same study, Wood and colleagues found that between August 1, 1996 and July 1, 2000, of the 1,422 patients who initiated HAART therapy, 25.2% (359) were people who used injection drugs. Of these 359, results showed that those who used injection drugs were less likely (p = 0.001) than the rest of the study participants to be at least 95% adherent (2003b). In 2002, a study by Arnsten and colleagues, found that active cocaine use was the strongest predictor of poor adherence, with the overall successful adherence being 27% for active cocaine users compared to 68% for participants who reported no cocaine use for the previous six months. Furthermore, in a study done by Cofrancesco et al. (2008), of the 1457 participants studied, people who were currently using heroin and crack/cocaine and who were on HAART were less likely to achieve viral suppression, which is indicative of poor antiretroviral adherence.

Most studies tend to associate poor adherence to the inconsistent, unpredictable, and chaotic lifestyles led by people who use illicit drugs (Hinkin, Barclay, Castellon, Levine, Durvasula, et al., 2007). In addition to the chaotic lifestyles resulting from compulsive drugseeking behaviours, people who use injection drugs often face issues such as homelessness and psychiatric illnesses, which can both severely complicate people's abilities to achieve successful adherence to HAART (Wood, Kerr, Tyndall & Montaner, 2008b; Palepu, Yip, Miller, Strathdee, O'Shaughnessy & Montaner, 2001). Wood and colleagues (2008b) completed an in-depth literature review into the barriers to HAART adherence among injection drug users and found that the barriers can generally be grouped into socio-structural, individual-level, and provider-based concerns.

Socio-structural barriers. The socio-structural barriers to achieving high levels of HAART adherence include incarceration, stigma, social exclusion, lack of or substandard housing, health

care systems, and illicit drug policy (Palepu et al., 2003; Wood et al., 2003b). A study by Kerr, Marshall, Walsh, Palepu, Tyndall, Montaner and colleagues (2005) found that the most frequently cited reason for discontinuing HAART among 160 participants of the VIDUS study was incarceration. Reasons for discontinuing HAART while incarcerated were explored in a discussion paper by de Bruyn (1998). He found that the structural characteristics of prisons and the associated routines of prison life make maintaining a HAART regimen difficult. This can be due to the drug dispensing times, dietary requirements, and issues involved in attending court and transfers. De Bruyn also noted that many people do not disclose their HIV status while in prison for fear of negative consequences such as intimidation and violence (1998). Furthermore, recent research by Small and colleagues (2009) found that suboptimal adherence while incarcerated may be linked to difficulties obtaining prescription medication within correctional facilities, poor relationships between prisoners and healthcare staff, and the high levels of discrimination towards both HIV status and injection drug use. A study by Room (2005) found that drug addiction received a higher rating of social disapproval than that of having a criminal record for burglary or not caring for one's children. This disapproval can be seen in the public's opinion concerning the setting of health care priorities, for example, illicit drug users should receive less priority in healthcare, as it is believed that they (illicit drug users) are ultimately responsible for their condition (Olsen, Richardson, Dolan & Menzel, 2003). Housing can also play a large part in one's ability to be adherent to HIV medications. Substandard living conditions can include crowded living situations, lack of privacy and security, lack of food security and cooking facilities, and inadequate sanitary facilities – all of which are proven to be vital to successful adherence (Krusi, Wood, Montaner & Kerr, 2010). The organization of health care systems can also be a barrier to adequate adherence. Highly compartmentalized health care

systems do not easily allow for individualized, comprehensive care (Krusi et al., 2010). Individual health care needs can include HIV specialty care, primary care, addictions care, and mental health care to name a few. Finally, illicit drug policy itself can present a major barrier to being adherent to treatment as prohibitory drug laws can negatively contribute to the participation in HIV treatment by causing insurmountable barriers between people who use injection drugs and healthcare services – exampled by the lack of needle exchange programs in the Canadian penitentiary system (Krusi et al., 2010).

Individual-level barriers. The individual-level barriers to HAART adherence include increases in intensity and frequency of illicit drug use, lower adherence self-efficacy, associated psychiatric and medical co-morbidities, and the perception of the negative side-effects of HAART (Stein et al., 2000; Kerr et al., 2004, Arnsten et al., 2007, Carrieri et al., 2006). Increases in intensity and frequency of illicit drug use were found to play a factor in reduction in adherence capabilities by Stein and colleagues (2000). They found that the only factor significantly associated with non-adherence was continued use of injection drugs. Adherence self-efficacy is the confidence that a person has in one's ability to adhere to a treatment plan (Johnson, Neilands, Dilworth, Morin, Remien and Chesney, 2007). Arnsten and colleagues (2007) found that self-efficacy was an important factor for 636 people who continued to use illicit drugs but were able to remain on HAART. Carrieri and colleagues (2006) corroborated evidence that links psychiatric morbidities with adherence to HAART. Additionally, Carrieri and colleagues (2006) found that side effects of HAART have the ability to not only influence adherence in the short term but can also influence long term adherence.

Provider based barriers. The provider based barriers to HAART adherence found in the literature describe that among healthcare providers, there is an underlying assumption that people

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who use injection drugs are not capable of achieving the high levels of adherence needed for viral suppression, and therefore clients should not be started on HAART until addiction issues are resolved (Wolfe, 2007; Strathdee et al., 1998; Celentano et al., 1998; Peretti-Watel et al., 2006). In a longitudinal study of 404 people who use injection drugs, Celentano and colleagues found that half of whom reported being actively involved in injection drug use – 49% (199) of the HAART-eligible participants reported taking no antiretrovirals at all (1998). Strathdee and colleagues' (1998) studied the barriers associated with free antiretroviral therapy for people who use injection drugs. They found that based on a combination HIV treatment experience of the physician and patient characteristics including sex, age, and enrolment in drug treatment programs that only 40% (71) of the 177 participants eligible for HAART received HIV medications.

On the other hand, there is literature that supports the idea that people who use injection drugs are able to maintain the high levels of adherence required of HAART when specific efforts are made to assist them. An example of such efforts is opiate replacement therapies including methadone and buprenorphine (Lert & Kazatchkine, 2007; Moatti, Carrieri, Spire, Gastaut, Cassuto, & Moreau, 2000). To further this point, Wood and colleagues (2003b) found that there is no evidence that conclusively indicates that people living with HIV and actively using injection drugs are any less likely to respond to HAART when provided with optimal therapy and experienced physicians.

HAART Adherence among Aboriginal People. Several studies have shown that Aboriginal people typically have less access to health care and prevention services. Barriers include the actual physical access and access to culturally appropriate health care – both of which are influential on one's ability to be adherent to HAART (Wood et al., 2008b; Lima, Kretz, Palepu, Bonner, Kerr,

Moore et al., 2006; Newman, Bonar, Greville, Thompson, Bessarab & Kippax, 2007). A study by Wood and colleagues found that Aboriginal people are more likely to die from AIDS- related complications without ever having accessed HAART treatment in British Columbia, despite universal, free access to HIV medications (2003). Additionally, Aboriginal people are less likely to have a treating physician that is experienced with HIV, and research has shown that physician experience is related to treatment success (Miller, Spittal, Wood, Chan, Schechter, Montaner, & Hogg, 2006). Furthermore, Aboriginal people receiving HAART have been found to be more likely to be living under the poverty line and in unstable housing – another factor that is strongly associated with low adherence and interruptions in treatment (Palepu et al., 2001). A study done in Western Australia on the barriers and incentives to HIV treatment among Aboriginal people found that fear of disclosure and discrimination, alcohol consumption, lack of stable housing, inability to afford nutritious food, and inadequate income were all factors in poor adherence to HAART therapy (Newman et al., 2007).

Comparable examples of adherence barriers faced by Aboriginal people can be found in the literature regarding adherence to Tuberculosis treatment among Aboriginal people – treatment regimes that are similar to HIV medication regimes, in terms of daily dosages and required high level of adherence. A study by Gibson, Cave, Doering, Ortiz, and Harms (2005) on the socio-cultural factors that influence prevention and treatment of Tuberculosis among Aboriginal and immigrant people found that English language proficiency, Tuberculosis-specific disease knowledge, and stigma were all factors associated with treatment adherence. Specifically among Aboriginal people, the stigma attached to being infected with Tuberculosis was a commonly cited barrier to medication adherence and was associated with the abandonment of treatment and delays in engagement of care (Gibson, et al., 2005). In the same study, Gibson and colleagues (2005)

found that all participants reported lengthiness of treatment¹¹ for Tuberculosis as an obstacle to adherence, as taking medications placed great constraints on daily life, such ability to care for children, ability to work full-time or attend school. Medication adherence is also attached to the accessibility of health care.

HAART Adherence among Aboriginal Injection Drug Users. There is very little research that focuses on HAART adherence among Aboriginal people who are current injection drug users. However, the literature supports the fact that within the adult Aboriginal population, injection drug use is considered one of the primary modes of HIV transmission, accounting for approximately 60% of new HIV infections in Vancouver, British Columbia (Marshall, Kerr, Livingstone, Li, Montaner, & Wood, 2008). Furthermore, studies have found that Aboriginal injection drug users have a slower uptake of HAART –29.2% compared to non-Aboriginal injection drug users for a slower uptake of time (Wood et al., 2006). *Barriers to accessing healthcare for Aboriginal people.* According to Lerat (2005), the experience of many Canadian Aboriginal people with the mainstream healthcare system has been overwhelmingly negative. Such interactions inevitably result in higher rates of non-compliance and reluctance to use mainstream health services (Lerat, 2005). McCall, Browne and Reimer-

Kirkham (2009) interviewed eight Aboriginal women with the goal of developing a greater understanding of the barriers, challenges, and successes of accessing healthcare services. Three main themes emerged from the data: fear of rejection, struggles with HIV symptoms, and living with the stigma associated with HIV (McCall et al., 2009). In Australia, Newman, Bonar,

¹¹ I reatment for Active Tuberculosis is divided into two phases the initial or intensive phase, when drugs are used in combination to kill iapidly replicating populations of *M tuberculosis* and to prevent the emergence of drug resistance, followed by the continuation phase, when drugs are used to kill slowly and intermittently replicating populations. The treatment regimens can include differing number of drugs and can range from 6/9/12 months in duration (Public Health Agency of Canada, 2007c)

Greville, Thompson, Ressarab and colleagues (2007) interviewed 20 Aboriginal people to discover some of the barriers Aboriginal people living with HIV faced when attempting to start HAART. They found that the barriers to HAART and general access to healthcare were fear of disclosure and discrimination, heavy alcohol consumption, and poverty – all factors, which can be generalized to Aboriginal Canadians (Newman et al., 2007). The same authors also found that for many Aboriginal people, maintaining social relationships, respect of friends and families, and maintaining normal everyday routines was a greater priority than their individual health. Jackson and Reimer (2005) conducted a nation-wide survey of 195 Aboriginal people living with HIV/AIDS (APHAs) in Canada. They found that the most common barriers to accessing healthcare services were logistical barriers, including long wait times at emergency departments; perceived poor HIV-related care, resulting in less desire to seek medical attention; and expressions of HIV stigma, racial prejudice, and homophobia that prevented full access to healthcare (Jackson & Reimer, 2005). In 2008, the Canadian Aboriginal AIDS Network (CAAN) commissioned a report to study the perceptions of care among Aboriginal people having AIDS and healthcare providers with the end goal of designing 'wise' practice guidelines for HIV health care providers who work with APHAs. The research consisted of 22 interviews with Aboriginal people living with HIV, and focus groups with primary and community-based HIV professionals (CAAN, 2008). The study found that the most commonly expressed reason for not accessing healthcare was the fear of experiencing stigma, racism, or homophobia from family, friends, and healthcare providers (CAAN, 2008). Safe care is thus paramount, when providing care to Aboriginal people. The next section of the thesis will examine the concept of culturally safe care, and how it is related to providing care for Canadian Aboriginal people living with HIV. Subsequently, with culturally safe care in mind, this section will explore the academic literature

for the aspects of healthcare that need to be modified to allow for maximum efficacy of treatment for Canadian Aboriginal peoples.

Provision of culturally safety. Cultural safety ¹² is defined as the on-going commitment to provide healthcare that is responsive to cultural diversity (National Aboriginal Health organization, 2008). Cultural safety readily adapts care to meet cultural values and beliefs, and promotes a continuous process of learning and sharing between the health care provider and client (College of Registered Nurses of Nova Scotia, 2006). Cultural safety within an Aboriginal health context means that the health care worker, whether Aboriginal or not, "can communicate competently with a patient in that patient's social, political, linguistic, economic, and spiritual realm" (National Aboriginal Health Organization, p.4, 2008). This means that the simple provision of physical and psychological care does not equate to culturally safety. Cultural safety is not just tolerating Canadian Aboriginals people's views and practices; it is encouraging and embracing Aboriginal views and practices. In terms of Canadian Aboriginal people, cultural safety entails a holistic approach to health that includes and respects traditional Aboriginal views of illness, and maintains the balance between the four realms of physical, spiritual, emotional and mental health (Mill et al., 2008).

Research conducted by Hamill and Dickey with American Aboriginal people suggests that due to a traumatic history of neglect and deception, Aboriginal people may be reluctant to seek health care services from non-Aboriginal providers (2005). In order to restore the balance and to achieve culturally safe care, Hamill and Dickey (2005) have made the following

¹² "Cultural safe care" is derived from the phrase "cultural safety" – a term developed in New Zealand in the 1980s Cultural safety is the effective nuising of a person/family from another culture by a nurse who has undertaken a process of reflection on their own cultural identity and recognizes the impact of the nuises' culture on their own nursing practice. Additionally, cultural safety empowers the users of the service to express degrees of felt risk or safety. Cultural safety recognizes that a patient who feels unsafe may not take full advantage of the health services being offered, and therefore avoid services until absolutely necessary (Papps and Ramsden, 1996)

suggestions: increase the awareness of the importance and impact of colonization on Aboriginal peoples, encourage acceptance and promotion of the practice of traditional approaches to healing, and become familiar with the communication style of Aboriginal people. In order to incorporate the aforementioned suggestions into current healthcare practice, we need to break down specifications of care to: assessment of medical conditions, direct care provision, counseling, and referral services provided.

Assessment of medical conditions. The foundation of health in Canadian Aboriginal people is based on a holistic approach, encompassing individuals' psychological, emotional, physical and spiritual well-being (Lerat, 2005). It is therefore important that when assessing the health care needs of Canadian Aboriginal people, the healthcare provider understands the health perspective of the individual. It is important to understand that although Western practitioners may see traditional Aboriginal healing practices as alternative, it is actually the other way around for many Canadian Aboriginal people, so it is vitally important that healthcare providers take the time to explain the rationale for health assessments and care provided. With that said, it is also important to recognize that many Canadian Aboriginal people are comfortable navigating and functioning within the Canadian healthcare system, that not all Aboriginal people value Aboriginal healing practices, and, that there are numerous different Aboriginal groups with different practices, beliefs, and customs.

Direct care provision. With the recognition that Western contemporary medicines are needed in the care of HIV, it is integral that they be integrated into Canadian Aboriginal people's holistic approach to care (Lerat, 2005). If the healthcare provider is able to offer some level of traditional health and wellness programs, it increases the chances that more Aboriginal people living with HIV will accept future care and support (Lerat, 2005). According to Lerat (2005), a

commonly used traditional practice by Canadian Aboriginal people are Healing Circles. The Healing Circle allows for the creation of a safe environment to talk about illnesses, and to share feelings without the worry of negative reactions by other people. A second commonly used health practice are traditional ceremonies, which allow for conscious contact with the Creator, allowing for the psychological, emotional, physical and spiritual parts of the body to align (Lerat, 2005). Another important practice is the use of traditional herbs, which are used for a smudging ceremony. The herbs most often used are tobacco, cedar, sage and sweetgrass (Lerat, 2005).

Counselling and referrals services. The ability of Canadian Aboriginal people to learn and connect with their traditional culture has resulted in an improved coping ability to deal with negative encounters and events – such as living with HIV (Lerat, 2005). In applying this concept to counselling and referrals, it has been shown that satisfaction in connecting with traditional culture in Canadian Aboriginal people is highest in those that are the sickest – i.e. advanced HIV disease (Lerat, 2005).

Knowledge gap

The key points presented in this chapter can be summarized in five brief points. Firstly, the epidemiology of HIV clearly demonstrates that Aboriginal people in Canada are at greater risk for HIV and have higher incidence rates than non-Aboriginal Canadians. Secondly, Aboriginal people typically have delayed access to HAART, and having Aboriginal ancestry is associated with a higher risk of dying without ever having accessed HAART. Thirdly, achieving the high levels of adherence to HAART needed for maximal viral suppression is very difficult. Fourthly, independent of each other both active injection drug use and being Aboriginal are factors associated with poor adherence to HAART. Finally, very little research has been done on identifying components of an adherence support program aimed at Aboriginal people on HAART who continue to use illicit injection drugs.

In carrying out this literature review, it has become apparent that there exists a gap in knowledge about the experience of HAART adherence for Aboriginal people who are also current injection drug users. Therefore it is imperative for further research to investigate how, that in a time for many, adherence to HAART is becoming a non-issue that a greater attempt is made to understand the issues affecting adherence for Aboriginal people who continue to use injection drugs. The aim of this study was to fill this gap. Specifically, this study provided the participants with an opportunity to tell their own stories of adherence to HAART, and inform how adherence support can be improved to facilitate greater adherence rates among Aboriginal people who use injection drugs. Four questions were asked of the participants: please tell me your story of living with HIV (and injection drug use); please tell me your story of living with HIV (and injection drug use); please tell me your story of HIV treatment; please tell me your story of being Aboriginal, HIV positive, and using injection drugs. I hope to contribute further information that will allow healthcare providers to develop and carry out HAART adherence support programs that better address the needs of Aboriginal people living with HIV who continue to inject illicit drugs.

Chapter Three: Methodology

Introduction

In this chapter, I will begin by locating myself within Aboriginal research. Next, I will discuss the fundamentals of qualitative research tradition and position grounded theory within this tradition. Additionally, a comprehensive discussion of the research design and methods used in this research project will be provided, specifically paying consideration to sample selection, data collection and analysis, methodological rigor, ethics, and the strengths and limitations of the research project. Finally, the research participant profiles will be presented.

In order to successfully meet the criteria of Aboriginal research, it is imperative that I respect Aboriginal culture and work within Aboriginal protocols for community-based research (Absolon & Willett, 2005). To do so, I will answer the following questions: (1) Who is doing the research? (2) How is the research being done? (3) What purpose does the research serve to the community (Absolon & Willet, 2005)? In order to *successfully* explain the protocol, the following discussion will be broken down into the following sections: locating myself within Aboriginal research, theoretical framework, methods, and analysis.

Locating Myself within Aboriginal Research

When conducting Aboriginal-based community research, it is important for the researcher to be cognizant of Aboriginal ways of knowing, and to be accountable for their own positionality (Absolon & Willett, 2005). Positionality is a way of locating oneself within Aboriginal research. Positioning is more than saying one is an American or Canadian, or from Vancouver or British Columbia; location is about the relationship the writer shares with the land, and language. It is about the spiritual, cosmological, political, economical, environmental and social elements in one's life (Absolon & Willett, 2005). The purpose and strength of using location in Aboriginal research is that,

It means revealing our identity to others; who we are, where we come from, our experiences that have shaped those things, and our intentions for the work we plan to do. Hence, 'location in Indigenous research, as in life, is a critical starting point' (Sinclair, 2003, p.122).

What Sinclair is saying, is that if a researcher wishes to conduct ethical research within Aboriginal communities - accurately represented research - then the researcher must show his/her positioning and connection to the intended research. Moreover, when a researcher locates (uses positionality), the message given to the research participants and Aboriginal community at large, is an understanding that the reason the researcher is gathering data and asking potentially difficult questions is to improve current community conditions, and that the hopeful outcomes of the research will be useful to the community (Absolon & Willett, 2005). By claiming location, I am acknowledging Aboriginal world views and Aboriginal "ways of knowing", thus transforming my research to fit within Aboriginal accepted ways of subjectivity, credibility, accountability and humanity.

Positioning Statement of Robert Sam Milligan. I was born April 1, 1974 in Vanderhoof British Columbia, Canada. My parents, William Robert Milligan (welder / fabricator / farmer, born in Sudbury, Ontario on April 14, 1944) and Elizabeth Wendy Walker (initially a stay–at–home mom turned school teacher, consummate volunteer, and then victim services coordinator at the Prince George RCMP detachment, born June 18, 1948 in Surrey, British Columbia) had moved to Vanderhoof in 1973 with their two daughters, to start a new life in Northern British Columbia. My parents had known each for several years, and my mother was actually married to one of my father's best friends. Unfortunately (but fortunately for me), my mother's first husband was killed in a hunting accident, leaving my mom as a 25-year-old pregnant widow, with one other daughter. My father, who at the request of my mother, helped during that first Christmas assembling presents, and took the opportunity to grab my mother's heart (a woman his parents always believed he loved). Soon that assistance and energy turned into love, marriage, adoption and the decision to move north.

My father, being a retired Canadian Navy gunner who had recently received his welding ticket, led the charge north to find a new home, and settled in Vanderhoof, the "geographical center of BC." I remember my father often saying, "If I had not found work here, Whitehorse was the next stop." My father worked all over British Columbia, and was often absent in my upbringing, but his words were never far, and his discipline was even closer. The one guiding principle my father taught me was, "Work hard, never ask for anything for free, and for God's sake, owe as little money as possible!" I often believed one of his worst fears would have been to be the father of a lazy child. Dad is not an educated man, with his formal education topping out at what he calls "high 8 low 9," but I would challenge anyone to have his knowledge and professional abilities in the construction industry – and I have to mention – I have never seen anyone get so worked up and angry over the evening CBC news hour. Dad was also a big education pusher. He was constantly, yet subtly, pushing us to do well in school, and he forbid any of us from going into a labour position: "It's too hard on your bodies. My kids will use their brains" was a message I heard for years. Dad was the consummate provider, making sure each of his kids was given all the opportunities he was denied, as long as we did not act spoiled; he would spoil us to no end.

My mother had many jobs when I was growing up, but perhaps the most difficult was being a mother of three rather different children. My oldest sister was wild at heart, and I am sure she rattled my mom's confidence in her parental abilities on a weekly basis. My middle sister was the quiet, reserved, never-do-anything-wrong academic superstar, who only challenged my parents with the boys she decided to date and her own tears of punishment if she ever came close to getting in trouble. I, on the other hand, was a walking medical disaster. I had the only medical chart that could be picked out from across the room at the local health clinic – you just had to locate the biggest one. I had epilepsy, poor vision, poor hearing, and poor language skills – leading too many years of academic struggle. I regularly put my face in front of moving objects and had a tendency to acquire infections like I was an obsessive collector of bacteria and viruses. This combination added up to a local doctor telling my parents to be prepared for the fact that I would have to live with them for the rest of their lives, as I would never be able to hold a fulltime job or take care of myself. Fortunately, my mom never really liked that doctor, and my father liked him even less and they vowed I would achieve everything the doctor said I would not. Mom ruled the house and family with an iron slipper that was thrown with deadly accuracy – she possessed a wicked curve, and was especially adept at hitting moving targets. The three of us were raised in a loving and happy home, but a home with rules. We were challenged to do the right thing, and supported when the right thing would lead us into trouble with so-called authority figures – high-school band and social studies teachers for example. My parents knew we witnessed them standing up for their rights and the rights of others, so although we were taught to respect our elders and were reprimanded in public for breaking certain rules, we were often praised in private.

We lived in the country on a farm, with the typical farm animals, and the responsibilities of farm kids. My first school was Mapes Elementary, a small rural school that had approximately 100 students. Demographically, the community was mostly Caucasian with a few Aboriginal kids. Retrospectively, all of the Aboriginal kids were in foster homes. I remember initially being friends with everybody, and not realizing a difference between white kids and Aboriginal kids, but as time went on, and the years past, I have to admit, I grew to look at Aboriginal people as second class citizens. The influences of my school, friends, town, teachers and at times the actions of the Aboriginal kid themselves, all led me to become what I am shamefully admitting to know now as being racist towards Aboriginal people. My thoughts were that they got paid to go to school, got everything for free, were always trying to fight or steal from me, did poorly in school, and were lazy...what judgmental thoughts coming from a kid who was never supposed to be able to take care of himself.

I went through elementary and high-school with a growing dislike and disdain of Aboriginal people – with the exception of two individuals. Vern was one of my best friends. He was, however, adopted into a white family, and had a more outwardly negative attitude towards other Aboriginal people than anyone I knew. I vividly, yet now sorrowfully, remember our first road trip together. We went to Banff. I will never forget, seeing first hand, how Vern was treated like a "typical-Indian," i.e. lazy, dumb, and second-class. I and our other friend just brushed it off, and pretended it did not happen – but I can still remember seeing the anger in Vern's face. Sadly, Vern was killed in a car accident when he was 21 years old. Randy was my other close Aboriginal friend. We met in grade 6 and had an instant kinship for years. I've lost track of him in recent times but often think of the gags we used to play together.

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It was in college, when I first started learning about the true position and plight of the Aboriginal people of Canada. I was on a bus in North Vancouver, and an Aboriginal woman had a shirt on that read "Aboriginal Holocaust, 1492 to ----." I was upset and wanted to verbally attack her, and blame her, and say it was her own fault, and if Aboriginal people weren't so lazy then they could be a productive part of society. Fortunately, I didn't say anything, mainly because I knew my parents would consider me in the wrong. What I did do, was develop a curiosity about Aboriginal history. I travelled around North America after that, working in many different locations, and was introduced to Aboriginal cultures in locales from Whitehorse to Haida Gwaii to New Mexico. I remember how the walls of racism that I had developed in my childhood began to breakdown.

I started nursing school in the fall of 2001, and immediately was challenged by several professors as we studied culture and culturally appropriate care – in fact I loved it, and knew that I wanted to work and learn from all cultures. After graduation, I went to work immediately in the Downtown Eastside of Vancouver. I worked at the supervised injection site, and was exposed to the severity of mental health, addictions, infectious disease, poverty and life on the outside of accepted popular culture. This was the first time I was introduced to the concepts of marginalization and colonization. I heard stories from clients I worked with about the horrors of residential school. It was at this time that I began to realize the extent of colonization on the Aboriginal peoples of Canada. It was at this time that I decided I needed to not only learn the truth, but to also challenge my beliefs and to start speaking out and challenge the popular notion of Aboriginal peoples. I started asking questions, and more importantly, I started listening to the stories of Aboriginal people who were born into lives where they were denied their ancestry,

denied their cultural identity, denied the ability to have a safe and family-orientated childhood, labelled as second class citizens, and labelled as a dying race.

In 2008, I started graduate school at the University of Northern British Columbia in Community Health Sciences. I also started work at Central Interior Native Health Society, a health clinic for Aboriginal people, and all people who are on or close to the street. I was hired as the HIV outreach nurse, but quickly realized that I was also expected to learn and embrace Aboriginal ways of knowing, teaching and learning. My education at UNBC was equally challenging: I was presented and challenged with Aboriginal history from the perspective of Aboriginal peoples. I took classes from Elders, and learned their stories, and listened to their perspective of the world. For the first time, I understood that Aboriginal peoples are unique to themselves not only as a race, but also unique to themselves as individuals. They are not darker skinned white people sitting in front of me, but, in fact, many Aboriginal people share a connection to the world that while not beyond comprehension to me, does push and exceed my reaches into the realm of spirituality, emotionality, physicality, and mentality.

It was this time that I knew I had finally opened my heart and mind, and become accepting of peoples' struggles and challenges within their lives. This is the first time my Dad's words of, "My kids will use their brains" really made sense to me.

This positionality of me is where I am today. I respect the fact that my location will change in the future as representations will change depending on the context, and the realities I am locating too. This is who I am today, not yesterday, not tomorrow.

Theoretical Framework

A qualitative study design was chosen for this study because of its strength in exploring the meanings of identified social phenomena as experienced by individuals themselves, in their natural context (Malterud, 2001). Qualitative research is used when little is known about a phenomenon, and the researcher is seeking to gain insight, knowledge, and understanding from an "insider's" point of view (Morse & Field, 1995). In terms of this research study, it is hoped that by adapting a qualitative design, deeper insights will be elicited into the broader clinical realities of the lived experience of Aboriginal people living with HIV and active injection drug use. Insight will be gained through developing a greater understanding of participant lives, experiences, emotions, and struggles, within the context of their lived realities.

This study will use a grounded theory (GT) approach in its qualitative analysis. GT places emphases on letting a theory emerge from the data, rather than trying to generate answers to fit into a theory (Creswell, 2008). One of the strengths of GT is its contribution in areas where little research has been done, such as the role of active injection drug on the adherence of Aboriginal Canadians. By using GT, the variables relative to the studied phenomena will be brought forth, allowing for future in-depth study (Chenitz & Swanson, 1985). Ultimately, by using GT, I hope to understand the phenomenon – IIAART adherence barriers – being studied as experienced, perceived and valued by the participants.

Grounded theory was chosen over other possible qualitative theoretical frameworks such as narrative analysis, ethnography and phenomenology as it truly allows for and even necessitates that the researcher use concepts generated from the data as opposed to the already identified and discussed concepts of other researchers (Glaser, 2002). In addition, the constant comparative nature of grounded theory enhances the conceptualizing and comparison of insights as they emerge from the data (Glaser, 2002), which will generate rich data, furthering the understanding of how active addiction influences adherence.

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Methods

Methods include the sample, data collection methods, analysis phase, and the ethical controls put in place to ensure the rigor of the research project. These will be addressed in turn. *Sample*. Nine participants were selected from a cohort of clients at Central Interior Native Health Society¹³ (CINHS) that are living with HIV infection and active addiction. A nominated sample technique was used by the researcher and coding team¹⁴ to generate potential participants who fit the study criteria of being in HAART and actively using injection drugs. Potential participants were then approached by the project researcher to evaluate their interest and readiness to participate in the project. Participants were required to self-identify as active injection drug users, and to have been on HAART for a minimum of one month at one point in time, with completed HIV related laboratory blood work. The definition of active drug user was self-reported. However, potential participants needed to have reported using illicit injection drugs in the previous month prior to study admission.¹⁵ Additionally, potential participants were asked to show evidence¹⁶ of fresh injection "track marks."¹⁷ Adherence to HAART was measured in two ways: self-reported HAART adherence, and laboratory records. Participants were required to sign a medical release of information form allowing the researcher access to history of HIV viral

¹³ Central Interior Native Health Society (CINHS) is a non-profit health clinic for all Aboriginal people and anyone who is on or close to the street CINHS recognizes the inequality in health status between Aboriginal Peoples and mainstream society, and strives to restore balance through a holistic approach to health care that promotes physical, spiritual, emotional and cultural haimony with all Aboriginal people who reside in north central British Columbia

¹⁴ The coding team is made up of staff members of the Aboriginal Caucus at Central Interior Native Health Society (CINHS) The Aboriginal Caucus is responsible for assisting the staff members at CINHS in learning and incorporating Aboriginal "ways of knowing" and cultural competencies Each Aboriginal Caucus member volunteered to be on the coding team

¹⁵ The time frame chosen for history of injection drug use is supported by the Vancouver Injection Drug User Study (VIDUS, Wood et al, 2009), and by the research of Strathdee et al, 1998

¹⁶ The VIDUS study requires that all potential participants show evidence of fresh track marks as part of the entrance requirements into the study cohort (Wood et al, 2009)

¹⁷ Chronic injection drug use can be confirmed by observing track marks from repeated injections into veins. Track marks are a linear area of tiny, dark needle punctures surrounded by an area of darkened or discolouted skin due to chronic inflammation. Track marks are often found in easily accessible sites, such as the antecubital fossa and forearms (O'Connor, 2008).
load levels.¹⁸ The requirement of being on HAART for one month and to have completed follow up lab work provided verification to clients self-reports of HAART adherence. If participants did not have appropriate lab work completed by their physicians, referrals were made for the required tests. For participants that reported low-adherence or who were not presently taking HAART, medical records were accessed to provide confirmation that the participant was at one time on HAART.

Participant profiles. The demographics of the research participants were as follows: there were nine total interviews conducted: five females, three males and one person who identified as transgendered. At the time of interview, five participants stated they lived in stable housing, and four classified their housing situation as "unstable". For the purposes of this research project, unstable housing is defined as living in a community shelter, staying at a friend's house or being homeless. The mean age of the participants was 41.4 years. The mean time that the participants had been aware of their HIV positive status was 7 years 5 months. The longest known HIV positive status time was 14 years and the shortest known HIV positive status time was 2 years 9 months. The mean time on HAART was 3 years 4 months. The longest time on HAART was 7 years 9 months and shortest time on HAART was 11 months. Five participants were on methadone¹⁹ maintenance treatment at the time of being interviewed. Five participants currently have an undetectable HIV viral load.²⁰ The range of the most recent CD4²¹ count was from 170-

¹⁸ Measuring viral load a month after starting highly-active antiretroviral therapy (HAART) can strongly predict which individuals will have a viral load below 50 copies/ml after six months of treatment. A viral load of less than 50 copies/ml is considered maximum viral suppression (Smith, Staszewski, Sabin, Nelson, Dauer, Gute et al., 2004)

¹⁹ Methadone maintenance treatment is one of the most widely used forms of treatment for people who are dependent on opiates Methadone itself is a long-acting synthetic opiate agonist. Methadone works by alleviating the symptoms of opiate withdrawal by stemming the chronic craving for opiates. Methadone is usually prescribed one oral dose daily to prevent the onset of opiate withdrawal symptoms - including anxiety, iestlessness, runny nose, tearing, nausea and vomiting - for 24 hours or longer http://www.hc-sc.gc.ca/hc-ps/pubs/adp-apd/methadone-bp-mp/background-contexte_eng.php

²⁰ Viral load is a numerical representation of the amount of HIV in your blood http://www.catie.ca

660. Four participants were up to date with their HIV related care with four participants having outstanding blood work, and or HIV recommended vaccinations. The mean length of time of using injection drugs was 19.75 years. The longest time using injection drug use was 29 years and the shortest time engaged in injection drug use was 10 years. Still, all participants reported periods of abstinence during their time using illicit injection drugs. The mean age of the participants when they started using injection drugs was 22.3 years. The youngest age of starting injection drug use was 11 years and the oldest was 44 years of age.

Number	Gender	Housing	Age	Year of	Time on	Methadone	Last PVL	Most	Year	Age
				HIV	HAART		<40	recent	started	started
				diagnoses	(years)			_ CD4	IDU	IDU
A	F	U	30	2003	2.9	Y	10.04.19	580	1981	11
В	Т	S	48	1997	7.9	Y	10.06.19	550	1981	19
C	F	S	32	2007	11	Y	10.07.13	660	1995	17
					months					
D	F	S	47	2008	1	Y	NEVER	220	1994	31
E	М	S	48	2003	2.7	N	10.03.01	260	1978	16
F	F	U	32	2001	2.5	Y	10.07.27	600	1995	17
G	М	U	58	2007	11.5	N	NEVER	390	1997	44
					months					
Н	M	U	42	2002	5	N	10.27.09	170	1988	20
Ι	F	S	36	2001	4.5	N	NEVER	500	2000	26

Table 1: summary of participant demographics

Housing U = unstable, S = stable

Data collection methods Semi-structured, open-ended, taped interviews and a review of the medical record for HIV viral load levels and CD4 markers were completed. The interviewer used the four scripted questions (appendix 1) in the initial interview. The interviews were conducted over a five month period from January 2010 to May 2010. All participants were offered the opportunity to smudge²² before the interview, and access both a counsellor and Elder

²¹ CD4 cells are part of the immune system and help protect the body from infection HIV attacks these types of cells and uses them to make more copies of HIV which weakens the immune system, making it unable to protect the body from illness and infection. Normal CD4 count for people without HIV is between 600-1200 cells per cubic millimetre of blood http://aids.about.com/od/technicalquestions/f/cd4.htm

²² The burning of sage, sweetgrass, and fungus is called smudging. It is traditionally used to prepare and putity a person, place or thing for a time of openness and truth in the presence of the Creator (Association of BC First Nations Treatment Piograms, 2009)

immediately following the interview. Nine interviews in total were completed; each lasted approximately fifty minutes to one hour. The interview process consisted of a revisiting of the informed consent and a re-explanation of the signed release forms. Once completed, the first audio recorded interview was transcribed verbatim by the researcher and the remaining audio interviews were transcribed verbatim by a professional. Each transcript was then proof read against the audio recording by the interviewer to ensure accuracy. Interview notes were also taken during each interview to highlight non-verbal messages and salient themes that emerged immediately during the interview process. Unfortunately, one interview could not be used because of poor sound quality. However, the field notes taken for the participant were used as support for themes in the coding process. It is also important to note that this participant declined a second interview. All participants were provided with a twenty dollar stipend in the form of a gift certificate to a drug store, grocery store, or donut shop of their choice in Prince George as compensation for their time.

The interviews consisted of four broad questions: *Please tell me your story of living with injection drug use? Please tell me your story of living with HIV (and injection drug use)? Please tell me your story of HIV treatment? Please tell me your story of being Aboriginal, HIV positive and an injection drug user?* Each participant was asked the four overarching questions which were followed with a series of more focused questions to help clarify and probe for greater detail and understanding. The interview questions were designed to create a comfortable environment for discussion. So justifiably not all questions were directly related to the research goal of examining the experience of that active injection drugs use has on adherence to antiretroviral treatment.

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Analysis phase. The analysis component of grounded theory begins with the initiation of data collection, and continues throughout the course of the research project. The researcher employed a narrative analysis using Microsoft Word and Microsoft Excel software to compare the data sets, using the three steps of grounded theory: open coding, axial coding, and selective coding (appendix 2). In order to maximize insight into the lived experiences of the research participants, parts of the analysis phase were conducted with the assistance of a coding team made up of three Aboriginal professionals who are working within healthcare in Prince George. I chose to ask for the assistance of the coding team in the open and selective coding stages because I believe that for this research to be truly representative of the lived experience of the research participants, an Aboriginal perspective must be used in the interpretation and analysis of the data. I believe that while the research is serving a personal purpose of helping me to achieve my requirements for my Masters degree, it also needs to equally serve the needs of the participants. My work must represent Aboriginal perspectives and particularly those directly involved in the study honestly, without distortion or stereotype. It should honour Aboriginal knowledge, tradition, and customs, and most importantly, it needs to be free of ethnocentric judgment and an interpretation that may be skewed by my colonial education if it is to be culturally and practically relevant.

Open coding. In the open coding step, effort was made to discover categories through the conceptualization of data groupings taken from individual interviews. The data was condensed into categories and assigned themes to assist with grouping. The two phases of open coding - conceptualizing and discovering categories, as identified by Strauss and Corbin (1998) were performed. Conceptualizing involved the breaking down of the data into actions, events, incidents and ideas, and then giving representative names or themes (Strauss & Corbin, 1998). This process required an in-depth analysis of the text, word-by-word, line-by-line, and phrase-

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by-phrase (Strauss & Corbin, 1998). Next, the discovering of categories was completed. This involved grouping the identified themes into common categories, at a higher and more abstract level (Strauss & Corbin, 1998). However, before the grouping of the themes into categories was finalized, a comparative analysis of both the 'properties'²³ and 'dimensions'²⁴ of each identified theme was completed (Strauss & Corbin, 1998). Once accomplished, the coding team was asked to verify the accuracy of the identified categories that emerged from the data. Once the coding team examined the data set, all necessary modifications were made to the identified categories.

Axial coding. The axial coding process is the second pass through the data, with more attention paid to the coded themes than the actual data. Axial coding involved the discovery of relationships between categories and subcategories, with the goal of understanding how categories related to subcategories in terms of 'properties' and 'dimensions' (Neuman, 1994; Strauss & Corbin, 1998). Effort was made to review, examine and order the themes by clustering the themes under the key overarching themes and secondary themes.

Selective coding. The selective coding process is where the incorporation and fine-tuning of the emerged themes took place. The overall aim of the selective coding process was the integration of themes at the dimensional level in order to accomplish the three goals identified by Strauss and Corbin (1998): the discovery of a theory, the validation of the relationship between concepts, and the detection of any themes which need further refinement. It is at this point in the coding process where I involved the participation of the coding team. We reviewed three randomly selected interviews looking for the subtleties of "Aboriginal context" that may have been overlooked by the researcher. This process involved the identification of selected passages from each interview and a discussion around its meaning and relation to "Aboriginal context".

²³ Properties explain the general or specific characteristics and attributes of a category (Strauss & Corbin, 1998)

²⁴ Dimensions define the varying range of the general properties of a category (Strauss & Corbin, 1998)

Ethical Controls. The high level of commitment to ethics in grounded theory enabled the researcher to fully immerse himself in the participants' lived experiences in a safe and non-threatening manner. Immersion permitted the interviewer a genuine attempt to understand the lived experiences of the participants' own understanding of the identified research phenomena. However, to be productive, immersion required that a deep understanding and trusting relationship be developed between the interviewer and participant. In order to achieve this relationship, several important control mechanisms were put in place: a gatekeeper, ethics permission, informed consent, confidentiality, and validity checking (Cresswell, 2008; Havercamp, 2005).

Gatekeeper. In grounded theory, the gatekeeper role is used to help facilitate access to places, people, events or documents. For the purposes of this project the gatekeeper was intended to be a staff member from Positive Living North (PLN)²⁵ in Prince George. Unfortunately, this role did not work out as the chaotic lifestyle of the participants, and the busy schedules of the PLN staff member and researcher made the scheduling of meetings very difficult. Fortunately, the researcher in his role as a Nurse Clinician at Central Interior Native Health Society has a respected role in the HIV community, and already has existing relationships with potential research participants. To ensure participants took part willingly, it is important to note that all participants were screened by the social worker or addictions counsellor at CINHS. Also, due to the chaotic lifestyle of the potential participants, it was required to be very flexible in the screening, selecting, consenting, and interviewing stages. Most interviews were rescheduled multiple times with the eventual decision made to allow the participants to drop into the researcher's place at work to see if the consenting and interview could happen immediately.

²⁵ Positive Living North is a community-based organization which provides education, prevention and HIV/AIDS support services in the Prince George region http://www.positivelivingnorth.ca/

Ethics permission. Permission was attained from the University of Northern British Columbia ethics committee, the University of Northern British Columbia School of Health Sciences, Central Interior Native Health Society, and Positive Living North. Small revisions were made in two areas after initial ethics permission was granted. Firstly, shortly after ethics approval the researcher received funding to provide a stipend for each of the clients. This funding was part of a fellowship the researcher obtained through the Universities Without Walls. The researcher informed the ethics chair of the funding and was given permission both verbal and via email to continue. Secondly, the role of gatekeeper changed as the realities of the role were not congruent with moving the project forward. This change was also communicated with ethics chair and supervisor prior to commencement.

Informed consent. Informed consent was obtained from the participants prior to commencing and throughout the interview. Clients were informed of the reasonably foreseeable factors that might influence their decision to participate in the study, including the potential risk of triggering relapse. Furthermore, voluntary participation was extensively discussed with potential participants', as to fully inform them of their right to withdraw from the research study at anytime. Additionally, the social worker or addictions counsellor met with potential research participants to discuss with them if they were comfortable participating in the research project, or if the existing relationship with the researcher was a coercive factor in their decision to participate.

Confidentiality. The level of detail and specificity that is generated in qualitative research can often make the guarantee of confidentiality difficult (Havercamp, 2005). Efforts were made to protect the identity of each participant by numerical coding of interviews and the changing of identifiable names and locations that were revealed during the interviews.

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Validity. The credibility of the research was checked by using peer examination and member checking. Peer examination used the coding team as a source of validation by allowing for analytical probing by the coding team, which helped uncover and explain different perspectives and assumptions by the researcher (Lincoln & Guba, 1985). Peer examination also allowed for the opportunity to test and defend emergent themes for plausibility (Lincoln & Guba, 1985). Member checking is when data, analytic categories, interpretations and conclusions are tested with members of those groups from whom the data were originally obtained (Lincoln & Guba, 1985). This was done after the final draft of the results was written. All of the research participants were given a copy of the results and asked to give input for accuracy and elaboration.

The transferability or the extent, to which the findings of the research can be generalized to a larger population, was evaluated by the use of a nominated sample, and a dense description of the research findings. Dense description is the describing of a phenomenon in sufficient detail so that evaluation about the extent that the study's conclusions are transferable to other times, settings, situations and people (Lincoln & Guba, 1985). Chapter four is part of the researcher's use of dense description, as chapter four creates a larger more in-depth picture of the research participants lived experience of HIV, and injection drug use outside of adherence to HAART.

The dependability of the research was addressed by using a dependability audit and the dense description process mentioned previously. How the dependability audit was used to evaluate the accuracy of the findings and to evaluate whether or not the findings, interpretations and conclusions are supported by the data (Creswell, 1998; Lincoln & Guba, 1985). The external audit was completed by the thesis supervisor, Dr. Josée Lavoie.

Finally, conformability was guaranteed by making use of analyst triangulation which allowed for the examination of findings from four different perspectives. Analyst triangulation

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was completed with the aid of the coding team. The purpose of analyst triangulation is to check selective perception and illuminate any blind spots that any one researcher may have when analyzing data (Creswell, 1998; Lincoln & Guba, 1985). Additionally, the use of personal reflexivity by locating myself in Aboriginal research by writing a positioning statement was used to ensure conformability. By using reflexivity the researcher disclosed how his background and position affected what he choose to investigate, the path the investigation took, the methodology chosen to conduct the research, and the framing and communication of conclusions" (Lincoln & Guba, 1985; Malterud, 2001).

Limitations of project

There are three primary limitations to this study. First, although the study participants were of varying ages, both male and female, and had a range of experiences, due to the relatively small sample size, and the fact that all participants were engaged with healthcare providers, the findings of this study may not be representative of all Aboriginal people living with HIV and active injection drug use in Prince George, BC. The small sample size, while representing a large proportion of the estimated population of Aboriginal people living with HIV, active injection drug use, and on HAART in Prince George, may not have generated all of the issues facing people in similar situations. The experiences and needs of Aboriginal people who are current injection drug users with little contact with community services may be under-represented in the research findings. Additionally, it is estimated that 27% of people living with HIV do not know they are infected with HIV (Canadian AIDS Treatment Exchange, 2009). Therefore, many more potential participants who are unknowingly living with HIV and using injection drugs in Prince George could greatly influence the research findings.

Secondly, that fact that the researcher is also the primary HIV nurse for all of the participants may have influenced the results. The idea of "self-censorship" may have been introduced into the interviews. From the researcher's perspective as a community HIV nurse clinician, relationships with patients follow a similar trajectory. Initially, the patient is reluctant to disclose personal and pertinent health information due to a lack of trust. As the relationship develops, more information is shared and a level of openness occurs based on trust that reaches full disclosure. However, as the relationship continues to develop, patients will reach a point where they do not want to "disappoint" their health care provider, and therefore withhold – self censorship – information, possibly resulting in compromised care. This situation is easily recognizable and addressed by the nurse by re-stressing the importance of communication and that no harm to the relationship or care will be incurred with full disclosure. For the purposes of this research, the researcher stressed to the participants the importance of honesty and that no change would occur in nurse/patient relationship or the care they would receive.

The third limitation of this study pertains to its qualitative methods, which rely heavily on the interpretation of interviews. The fact that the researcher is Caucasian and the participants were all Aboriginal may have led to interpretation errors during the identification of themes. Grounded theory implores in-depth analysis and interpretation of interviews, which requires an astute understanding of the participants. The use of the coding team – which was made up of Aboriginal professionals – was an attempt by the researcher to minimize this potential limitation.

Chapter Four: Results – Participant Responses to Questions

Introduction

The purpose of this chapter is to provide the reader with a greater insight into the daily lives of the research participants in terms of how HIV and injection drug use are a part of their everyday lives. This chapter is not intended to be analytical in nature. What this chapter does provide is a demographic overview of Prince George, British Columbia in terms of population, healthcare and community services, and HIV specific health services. Next, a sample of the research participant's answers will be provided verbatim in an attempt to provide the reader with a sense of intimacy with the participant's mental, spiritual, physical and emotional connection to their experience with injection drug use and HAART within the community of Prince George. A detailed analysis and discussion will be provided in chapter five.

Demographics of Prince George

The city of Prince George proper contains several areas: South Fort George, the Hart, the residential and light industrial neighbourhoods north of the Nechako River, College Heights, and the Bowl – an area of the city that includes most of the city and the downtown.

Prince George is home to 83,225 people, with Aboriginal people accounting for 10.6% (8,850) of the total population within city limits (Statistics Canada, 2007). The average annual income in Prince George is nearly \$40,000 (Statistics Canada, 2007). The average cost of purchasing a home in Prince George in 2007 was \$240,245, and the average cost of renting a home in 2007 was \$650 monthly (Statistics Canada, 2007). According to British Columbia Statistics, 3.7% of Prince George residents are receiving income assistance, as compared to 1.7% of all British Columbian residents (British Columbia Statistics, 2009). A single person who is expected to work but is on income assistance receives \$638.92 per month. A person who is

labelled with persistent multiple barriers²⁶ receives \$686 84, and a single person with a disability that prevents him or her from working receives \$940 69 (Province of British Columbia, 2010)

The health and community services that are offered in Prince George include the University Hospital of Northern British Columbia (UHNBC) The hospital has 209 acute care beds which include 10 combined intensive care unit/critical care unit beds, 18 paediatric beds, 21 maternity beds, and 15 beds in the rehabilitation unit In addition, there are five full time operating rooms There are also 72 extended care beds in Jubilee Lodge, as well as 37 chemical dependency beds There are approximately 120 physicians on staff at UHNBC, of whom, 55 are specialists Public health services offered in Prince George include women's health services, children and family services, communicable disease prevention and control, dental prevention services, hearing services, nursing support services, school and youth health, and speechlanguage services Mental health and addiction services include the Community Response Unit (CRU), the Community Acute Stabilization Team (CAST), the Community Outreach and Assertive Service Team (COAST), Inpatient and Intense Adult Mental Health Services, Adult Withdrawal Management Unit (Detox), Methadone programs, eating disorder clinics, Adolescent Psychiatric Assessment Unit (APAU), Youth Mental Health and Addiction Services, and the Nechako Youth Program Additionally, there are seven community shelters in Prince George There is one co-ed shelter in downtown Prince George serving anyone over the age of 19 There is one shelter serving adult males, and one shelter serving males transitioning out of correctional institutions Three shelters serve women - two of which can accommodate women with their

²⁶ The Persons with Persistent Multiple Barriers (PPMB) category provides assistance to clients who have long-term barriers to employment that are not expected to be overcome in the short term despite all reasonable steps by the client PPMB clients are exempt from employment obligations

⁽http://www.gov.bc.ca/meia/online_resource/employment_planning_and_exemptions/ppmb/)

children. Finally, there is one shelter serving children who are in the care of the Ministry of Children and Family Development.

Prince George has a regional correctional centre for adults sentenced in provincial court. There are a variety of internal and external programs available for inmates. These programs include substance abuse management, violence prevention, respectful relationships, breaking barriers (cognitive skills), alcoholics / narcotics anonymous, vocational programs, educational programs and Native brotherhood.

In terms of services for people living with HIV in Prince George, there is one health clinic – Central Interior Native Health Society (CINHS) – that specializes in HIV care. This clinic serves all Aboriginal people and anyone who is living on or close to the street. Moreover, CINHS serves all people, regardless of ethnicity or socio-economic status who are living with HIV. There is one infectious disease specialist who provides services to all residents in Northern British Columbia. This specialist works both out of his office, and at CINHS. Additionally, Prince George has one AIDS service organization that acts as a drop-in centre for people living with HIV and provides social support. As well, there is an AIDS prevention program operated by the Northern Health Authority, with services including a needle exchange, immunizations, referrals, and nursing assessments. Finally, several of the downtown pharmacies provide daily witnessed dispensing of methadone and HAART.

Regardless of the above listed services in Prince George, it is estimated that 10,000-15,000 people living in Prince George do not have a family physician (Godwin, personal communication, 2011). Additionally, according to the British Columbia College of Physicians and Surgeons as of February 1st, 2011 there are no physicians in Prince George accepting new patients (College of Physicians and Surgeons of British Columbia, 2011).

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Interview Results – How Prince George reflects in participants' stories

With the previously mentioned demographical description of Prince George in mind, a sample of the responses provided by the participants to each of the four broad questions will be provided to help understand the context of the participants' realities of living with HIV and active injection drug use in Prince George.

Living with HIV and injection drug use

When asked to reflect on their present day feelings of living with HIV and injection drug use, none of the statements expressed by the participants reflected on the city of Prince George. Instead, responses indicated a more internal understanding of living with HIV and injection drug use, as demonstrated by the following quotes,

Participant 009: "Well, [injection drug use] plays a really predominant role in my life. It is something that I think about all the time. Uh, it's my partner in life now. It is somebody, it is something I live with every day, it's something I think about every day. Now if I'm not careful, I can let it kill me, but if I do this properly, I can live longer and have a somewhat normal life and be healthy."

Participant 004: "Ya, I do [have HIV]. And that's because of the people around me keep throwing it in my face, because I've always been honest about having HIV". Participant 005: "No. No, not at all [thoughts of HIV]. Um it just comes in flashes because I try to um, push that part of my life away from me and try not to dwell on it because I find if you dwell on it, um you only harm yourself. Um, so I...try to um, avoid lots of thought about HIV. The only thoughts that come to me about HIV is when I'm at um, [AIDS service organization]... doing classes and I try to read into it and stuff like that about my body and how to care for myself and how to care for my

own body and my body functions to learn about HIV um, to protect myself and to be able to live longer. Because at one time, I didn't give a fuck about living at all. When I first found out I had HIV. I didn't give two shits about anything."

HIV Treatment – Antiretroviral medication (HAART)

When asked to tell their stories of HIV treatment, the statements expressed by the participants that reflected on the city of Prince George included references to the University Hospital of Northern British Columbia, the AIDS service organization (ASO) in town and the community shelters,

Participant 005: "Well, I had several doctors come in, I believe [the doctor]... was one of them, into Prince George Hospital, I mean Prince George Hospital as per se itself is not very fuckin' helpful in any way but the doctors were helpful. Um, [the doctor]... and [another doctor]... and a few others um, and when they came in and administered certain drugs to me they helped me a great deal and they helped me to start um, uh, heal. And built my antibodies and helped me to walk again and hold cups again and it brought a lot of my health back."

Participant 009: "You know what, I don't even have to dream it, you know I got [AIDS service organization or ASO]...um, and inside [ASO]... is [staff]..., [staff]..., [staff]... and me and the fact that it's a phone call away if I ever feel kind of shaky. Then there's here, [Aboriginal health clinic]..., there's you [Nurse]..., there's [Nurse]..., there's [Doctor]..., there's the ladies at the front desk, who when I call sometimes, they can tell by my voice I'm kinda like not in a really very stable place, they say hang on, we'll hook you up with somebody, we'll get somebody. And you know what, I'll sit there and go whoa, okay and these ladies are working. They're awesome. They're trying to find somebody for me to talk to or hook me up with somebody right now who can get me through this."

Participant 005: "The house that I have, the stable provisions that I have, the home that was provided me by [community shelter]..., the regular checkups that they provide me, like come in and check on me. Like um, certain individuals like [staff]... and that, that come in and check on me, like she'll come upstairs and check on me four times a day just to make sure I'm okay."

Participant 006: "Well having support from the [ASO]..., having support from [Pharmacy]..., you know, them giving it to me, having support from [Aboriginal health clinic].... I don't know a lot about the meds, I just know they're helping me." Participant 001: "Eventually I would like to get my methadone where I get carries²⁷ because having to come down town everyday was putting myself at risk of using again, it gets stressful having to go in every single day to the pharmacy."

Participant 005: "Staying in the home that I have and um, the amount of support I get from [community shelter]..., helps me stay clean. I mean, because um, they interact with me quite a bit in a lot of stages in my life to help me obtain things I need in my life like my false teeth, um, generally help me with Welfare so I don't get into a depressed mood and in a state of anger and that helps me a lot from turning to drugs."

Unfortunately, the research participants also pointed out those specific demographics of Prince George – the concentration of public housing, affordable housing, and shelters located in the core area of town where drug dealers are located – that contribute to using injection drugs. For example,

²⁷ "Carries" refers to the ability to pick up methadone for more than one day at a time Usually, methadone is prescribed as "daily witnessed ingestion". Once a methadone patient earns trust with the provider the next step is to give the patient methadone "carries"

Participant 006 "Drug logging²⁸, their talking, at [community shelter] where I live, they're talking, you know, I'm going to go out and I'm going to get a rock²⁹ and this or that Oh I got so high the other night you should've seen me, you know, they know they just talk and talk about drugs, talk about drugs that's all they do It's hard to get away from it You can't go into your own room and have alone-time There's nowhere to go "

Participant 004[•] "Ya, um, being around people that uh I'm around all the time They're a big trigger Because everybody I'm around is on drugs, and that's where I live And uh when even when we try to sleep there's people outside our windows uh yelling up at one of the girl's place because she does sell rock so uh them constantly yelling at her window is a big trigger and plus I live next door to a Laundromat, um, slash broken down apartment building where they sell drugs out of too and they're constantly yelling up to that place, to a dude's place there for them to let'em in, open the door and that is a big trigger Uh, so ya, just being where I'm at is a big trigger." Participant 006 "The downtown area Being around people, people talking, drug logging, you know seeing it, hearing it, smelling it You know."

Participant 008 "Downtown Well, actually not so much downtown anymore, where I live I live right on [street name] and [street name] , I got four ciack shacks³⁰ surrounding me So where I live is pretty bad Downtown's actually cleaned up It's actually really not bad down here anymore like it used to be It was pretty bad " Participant 001 " leaving [city] and being in a different place did help, where I did not know other people who did drugs That's what kept me clean was being away

²⁸ Drug logging is a slang term used in Prince George when people talk about using illicit drugs

²⁹ Rock refers to a slang term for crack cocarne (http://www.urbandictionary.com/define.php?term_rock)

 $^{^{30}}$ Crack shack is a slang term used for a residence where illicit drug users can purchase and use illicit drugs

from [city]... and all my peers that I knew, dealers, prostitutes, and the people that hang downtown, so my year away from [city]... after I went a-wall was uhm...time for me to get clean and I only did that because I did not know anybody in that area and so that's what kept me clean."

When asked how HIV treatment could work better for them, many participants spoke of the cultural dynamics of the Prince George community,

Participant 005: "How? By not treating us like we're a fuckin' infection or centering us out or yelling out in the fuckin' emergency rooms for example, 'oh, okay, you got HIV, let's go over here.' Like without fucking care that other people hear about it, because the stigma just in general about us fucking being HIV and what goes in a person's first fuckin' thought, oh, stay away from them. I mean the way we're directed, the way we're handled is all wrong."

Participant 008: "Big time here. Here it's a big time thing [stigma], especially if you're a drug user on the streets down here and they find out you're positive. Especially (who's they?) people that are living like down in this area. Especially if you're a working girl (mhm) like shit happens. Like people have been beat up. Like they'll be jumping into a john's vehicle and people will be yelling, 'Don't take her, she's HIV positive, you know, she's got blah, blah, blah,' you're labelled. Right? And then you're pushed away. Right. But now, that was a few years ago but now I see that almost 80% of the street people down here are positive so now it's like, it's more of, they just stick together and the rest stay away. You know, they just literally stay away from you. It's fear. Right? They don't want it and I can understand they don't want it. But people are misinformed. Like they don't want to hug you. Can I get a drink off your pop, like oh my God, it's the end of the world, right. It took me four years to educate my aunt cause she wouldn't even let me make her a coffee cause she, you know, and it took me quite awhile to educate her. You know what, if I make you a coffee, it's alright. You know, so I helped her out, lack of education, plain and simple."

Aboriginal Traditions in participants' lives.

When asked about Aboriginal traditions in their lives, a few of the participants responded that they considered Aboriginal traditions an important component of health in their lives. However, no references to the city of Prince George or its community services can be found within the stories told by the research participants. When asked to speak about living with HIV, active injection drug, and being Aboriginal, several strong statements that reflected on the community of Prince George emerged,

Participant 008: "I think that because of and I know that people hear this a lot, but nowadays the way we were raised, who we are, I was raised to be a drug dealer. I was raised around, like I remember watching people shoot up when I was 10 or 11 years old. I was raised in this environment and every Aboriginal family I know, every person I talk to was also raised in this environment, around alcohol, drugs and violence. So how do you fix something that has been ingrained in you since you were a baby? So that's what they need to figure out, is how can we reprogram an entire race of people. It's pretty much. And I've been thinking about it and I sit at home and think about it and I don't know. The only thing that works for me is like I said my mom. Like she's an old traditional woman, she was raised in the bush and I have enough respect for her that I will stay clean over the summer and bring her berry picking and do all these things she needs to do because I have that respect for her but 90% of us haven't got that respect anymore. We've lost it."

Participant 005: "I mean not all of us live the same way everybody else does, as say you honkey, or other people. We don't get the same fuckin' 9-5 life as everybody else. We don't get that as being Aboriginal. We're pushed into fuckin' alleys and cricks and crevasses in the road and we don't get a normal life and everybody else has a lot of us around here. But as being Aboriginal, the most beneficial way is when we have a stable home, a stable home where our rent is sent direct, where it's a setup like that are made easier for us and where we don't have to walk so far and stuff like this because we don't have the same energy as everybody else and everything else." Participant 005: "Doctors should be re-fuckin' trained and so should nurses where HIV patients are concerned and Aboriginals in general. That we're fuckin' people like everybody else and we were here first before all of them, you guys invaded us, you guys infected us. With not just HIV but with everything else. It's been a lot of abuse. That's the way I feel, that's what I have to say. Not only that, you guys got to show more love and concern where we're concerned. I mean why do you think some of us go out and do what we fuckin' do when some of us even, like other people I've seen infect other people and I don't how they can just go around infecting other people without fuckin' concern for the other person's life but I guess that's because they've been shown nothing but the same fuckin' love and concern that they've been shown from other people in the community."

Participant 009: "But you know what, like you said, my life has not exactly been very easy because I'm an Aboriginal injection drug user and then you throw HIV in there and people are like, 'Oh my God' and you know, I've actually had people get this look on their face like holy frick and they want to run. And I'm like; you know that doesn't make me feel very good. It makes me feel very, very small. It doesn't do very much for my own personal value either cause it doesn't make me feel very good. It makes me feel less of a person and it hurts."

Participant 006: "It's hard because, you know, people look at me and they judge right away. 'Oh, she's a, she's a crack head, she's a hooker, she's probably got HIV, she's probably got AIDS' and when they really do find out they judge me and uh, it's hard, I don't like it. It hurts."

Conclusion

This chapter provided a verbatim narrative of the participants' lived experiences in terms of their realities of being Aboriginal and living with HIV and active injection drug use in Prince George, British Columbia. This chapter reviewed the demographics of Prince George, and explored current health and service organizations in the community. It then provided direct quotes from the participants that examined how they perceive themselves fitting into the demographics of Prince George, in terms of the four broad research questions. This chapter provided a brief glimpse into the lived realities of each participant, and provided the reader with a better understanding of the issues faced by participants while living in Prince George. Chapter five will discuss the findings of this research project.

Chapter Five: Discussion of the Findings

Introduction

The main purpose of this study was to identify how healthcare providers can better support Aboriginal people who are injection drug users in their goal of achieving HAART adherence rates over 95%. The Grounded Theory design of the study resulted in nine narrative scripts which explored the lived experience of HIV and injection drug use of each participant. The following chapter will first give a brief overview of the participants' insights into living with HIV and active injection drug use. It then discusses the salient points uncovered in the interviews, and how these points relate or contrast to what is known in current academic literature. Additionally, when available, Aboriginal specific literature is discussed to help identify differences in Aboriginal and non-Aboriginal populations in terms of the pertinent discussion points. The main areas that will be discussed are *Living with HIV and injection drug use; HIV treatment – Highly Active Antiretroviral Therapy (HAART); and HIV, IDU, and being Aboriginal*.

Living with HIV and injection drug use.

In order to gain an understanding of the lived experience of people living with HIV and injection drug use, the first question asked of participants was, "What is your story of living with HIV and injection drug use?" The resonant statement articulated was that HIV and injection drug is always on participants' minds. However, when the actual statements of the research participants were analyzed, it is not clear if they meant that HIV *and* injection drug use was on their minds all the time, or if it was only HIV that was front and center in their thoughts. Participant 009 spoke of the predominant role that 'it' plays in her life and that if she "does not play it safe, it can kill her". The notion of "playing it safe" could reflect either on HIV or

injection drug use, but she went on, and spoke of "doing this properly" in order to "live a normal life." The embedded reasoning suggests that she was talking only about her HIV. Participant 001 only spoke of HIV and the burden of taking medication and made no mention of injection drug use and the role it played in her life. Participant 004 spoke of not being able to forget about HIV because she was consistently reminded of it every day by her peers and the physical environments she visits – specifically, AIDS service organizations. Participant 003 stated a similar coded message when he talked about how he has "it", when discussing his roommate's knowledge of his HIV status. The two clients who spoke about injection drug use only spoke indirectly about it, as exampled by participant 008, who commented that HIV affected everything she did from sleeping to the types of food she ate, to how she disposed of her injection equipment.

This avoidance of recognizing living life with both HIV and injection drug use can also be seen in the statements of the two participants who stated that HIV and injection drug use were not on their minds every day. Participant 005 spoke of only thinking about HIV in flashes and that she tried to avoid thinking about HIV. She made no mention of injection drug use. A similar theme was expressed by participant 006, who stated that she could forget about her HIV infection but knows it is in her body and that she only becomes outwardly aware of living with HIV when she is sick.

HIV treatment – Highly Active Antiretroviral Therapy (HAART).

This section explores four broad categories: the importance of treating HIV, enablers / facilitators and to adherence, barriers to taking HAART and participant recommended changes to HAART adherence support for better outcomes.

The importance of treating HIV. When asked if treatment for HIV was important, seven participants responded resolutely yes. When asked to expand on why it is important to take HAART, the underlying theme that emerged was that the participants wanted to live - more importantly – participants wanted to live healthier lives with greater quality than they were living before they started HAART. Participant 009 illustrated this idea of a "better life" when he spoke of what he hoped HAART would do for him in his statement, "I wanted quality of life and [HAART]... was also going to help me extend my quantity of life." Additionally, participants commented on the urgency or 'last chance' feelings that they had when the option of treatment was presented to them. Participant 008 described watching her cousin die from HIV and not wanting the same outcome for herself. Although this participant identified that she relapses on illicit drugs often, and will miss taking HAART, she claimed to recognize the importance of treating her HIV. A few of the participants also reported that even with the negative side effects associated with HAART, the benefits gained by taking the medications far outweigh the nuisances of nausea and diarrhoea. An interesting insight on the management of HAART-related side effects came from participant 006, when she said that she was "scared" of the potential side effects, but then realized that if she could use illicit drugs and deal with the effects of being high and "tweaking,"³¹ then she could manage the possibility of the side effects from HAART.

The beliefs and ideas presented by the research participants aligned closely to what can be found in the current academic literature examining peoples' perceived benefits, in terms of the quality of life for people taking HAART. Firstly, a study by Watt and colleagues (2009) on the facilitators of adherence to HAART examined 36 patients taking HAART for the first time. The study found that patients were more motivated to continue with HAART if their health status

³¹ Tweaking is a slang expression used for diug-induced paranoia, peaking on speed, or desperately searching for crack. Often people who are tweaking pay increased attention to trivial tasks. http://alcoholism.about.com/od/slang/g/tweaking.htm, http://www.ubandictionary.com/define.php?term=tweak

improved once commencing HAART. Furthermore, Ware and colleagues (2006) conducted 214 qualitative interviews with 52 HIV positive active drug users with the intent of examining how social relationships and stigma affected adherence to HAART. The study found that people living with HIV worked to create new personal identities that reflected the improved health status that HAART had helped them achieve (Ware, Wyatt, & Tugenberg, 2006). Interestingly, the study also found that as people successfully navigated HAART and built new identities reflective of improved health, adherence could be compromised, as the "strictness" of HAART started to interfere with other interests. Therefore, Ware and colleagues (2006) demonstrated that in order to be successful with long term adherence, the balance between life and health must be considered. The idea of creating new identities reported by Ware and colleagues are also supported in this research study, as exampled by Participant 006 when she reported that she realized that if she could manage a life of addiction and the resulting effects, then she could surely manage the side effects of HAART. Participant 006 was able to bridge the knowledge that she has gained from many years of injection drug use to that of how she can be successful on HAART. Flowers, Davis, Hart, Rosengarten, Frankis and Imrie (2006) conducted interviews with thirty Africans living in the United Kingdom, and found that HIV had the ability to take on a "master status" persona and obliterate the personal identification of people living with HIV. A person's status and self-identity were replaced with a social label that was, in part, constructed by the terminology that follows people living with HIV: antibody testing, patient viral load, and CD4 count (Flowers et al., 2006). In India, a study examining the barriers and facilitators to successful HAART involving 60 people receiving HJV primary care (33 on HAART, 27 not on HAART), found that the most frequently perceived benefits of high adherence were HIV disease

management, better overall health, living longer and gaining weight (Kumarasamy, Safren, Raminanai, Pickard, James, Krishnan et al., 2005).

Enablers / facilitators of HAART. When asked, "What helps you remember to take HAART?" the participants answered: fear; trust in their healthcare provider; having a routine they follow; and the support they receive from AIDS services organizations, family, and friends.

Fear. Fear – understanding the health consequences of what missing a dose could cause – was the most commonly reported theme that emerged when participants were asked, "What helps you remember to take HAART?" When asked to elaborate on their understanding of the consequences of not taking HAART as prescribed by their physicians, three participants spoke of fear of becoming resistant to HAART, two spoke of the fear of dying, and one participant spoke of fear of acquiring opportunistic infections³² that could result from poor adherence.

Participant 009 described the connection he associated between life and death with his medications when he said matter of factly, "Being scared.....fear of dying, fear of getting sick.....fear of my body just going okay you know what, you had your chance, bye, and just shutting down on me." Participant 008 and 009 both shared an expressed commitment to taking HAART: one perceived HAART as an opportunity for improved health, while the other viewed it as a "last chance" at life. Participant 006 and Participant 004 both spoke of how they feared becoming resistant to their particular HAART medications. The thought of having to take more pills as a consequence of poor adherence was motivation to help them remain adherent.

³⁷ Opportunistic infections occur at different stages of HIV infection. Examples of opportunistic infections in the early stages of HIV include tuberculosis, malaria, bacterial pneumonia, herpes zoster, staphylococcal skin infections and septicaemia. These are diseases that people with normal immune systems can also acquire, but with HIV, they occur at a much higher rate. It also takes longer for a person with HIV to recover from such infections than it takes for someone with a healthy immune system http://www aveit.org/hiv-opportunistic-infections htm.

Participant 006 elaborated that she had spent three months working on becoming adherent and that she did not want to "waste" that effort. Participant 004 summed up her fear of having to switch HAART regimes when she expressed the "horror" she felt when she thought about how other people living with HIV need to take multiple pills, multiple times a day. Finally, Participant 001 described that her feelings of fear were imbedded in the possibility of acquiring opportunistic infections from the resulting fall in CD4 cell count from poor adherence.

The statements of the participants showed a clear link in their understanding of the importance of high adherence to HAART, and the quality of life and decreased morbidity they could expect to receive. The participants made the connection between low adherence to HAART and the accelerated progression of HIV. However, the connection that was not spoken of by the participants was the associated morbidities that continued injection drug use could cause in relation to their HIV and health status. This missed connection could be attributed to a number of factors, including but not limited to: denial of addiction, lack of addiction treatment programs, lack of access to health services, and lack of knowledge of the negative consequences of continued injection drug use. Additionally, the relationship between the interviewer and the participants must be considered as the participants may have felt that by admitting the connection between continued injection drug use and their health status, they might "disappoint" the researcher, and possibly influence future care received from the researcher in his role as HIV nurse clinician.

In examining the literature, while unable to identify any Aboriginal specific health consequences, there was an abundance of literature that addressed the potential morbidities that could affect the quality of life of people who are dedicated to HAART, but who continue to use injection drugs. A 30-month longitudinal study conducted by Baum, Rafie, Lai, Sales, Page and

Campa (2009) on 222 people living with HIV, found that independent of HAART, people who actively injected crack-cocaine had an accelerated decline of the CD4 cell count and an elevated HIV viral load count - to levels considered diagnostic of AIDS. Palepu, Tyndall, Yip, O'Shaughnessy, Hogg and Montaner (2003) looked at 578 people living in British Columbia who were prescribed HAART from 1996-2000, and found that people who continued to use injection drugs were less likely to achieve maximum HIV viral suppression. Lucas, Gebo, Chaisson and Moore (2002) interviewed 695 people living with HIV to study the effects of drug and alcohol abuse on HAART treatment outcomes. They found that drug use was strongly associated with worsening adherence rates, decreased HIV viral suppression, and blunted CD4 cell increases. Lloyd-Smith, Brodkin, Wood, Kerr, Tyndall, et al., (2006) studied the impact of HAART and injection drug use on the life expectancy of 2003 participants in the HOMER and BART studies in Vancouver, British Columbia. They found that people who were infected with HIV and used injection drugs had an additional 23.0-24.5 years of life expectancy at age 20; as compared to 38.9 additional years of life expectancy for people taking HAART who did not inject drugs (Lloyd-Smith et al., 2006). These findings suggest that there are competing causes of death for people who are HIV positive and who use injection drugs. Tyndall, Craib, Currie, Li, O'Shaughnessy and Schechter (2001) found that the leading cause of death for people who were HIV positive and used injection drugs was HIV-related illness – including advanced HIV disease, pneumocystis carinni pneumonia, and TB – which accounted for 34% of total deaths. Other causes of death were overdose 25%, accident 4.6%, bacterial infection 20%, liver failure 12%, suicide 4.6%, and homicide 3%. Lucas, Griswold, Gebo, Keruly, Chaisson and Moore (2006) looked at illicit drug use and its effects on HIV disease progression in 1,851 people on HAART who were classified as non drug users, intermittent drug users and persistent drug users. They

found that when compared to non drug users, intermittent drug users had a twofold increased risk of death and persistent drug users had a threefold increased risk of death (Lucas et al., 2006). Furthermore, Lucas and colleagues found that persistent drug users had a twofold risk of developing new opportunistic infections as compared to non drug users (2006). Thorpe, Frederick, Pitt, Cheng, Watts, and colleagues (2004) studied the effects of drug use on HIV disease progression in 1148 women living with HIV and with a history of drug use. The study found that when compared to non-drug using women, women who used drugs had a higher risk of developing opportunistic infections, specifically herpes, pulmonary tuberculosis and recurrent pneumonia (Thorpe et al., 2004). Cook and colleagues (2008) examined crack-cocaine use and HIV disease progression among 1,686 HIV positive women. The study found that persistent crack-cocaine users were greater than three times more likely than non-users to die from AIDSrelated causes, even when controlling for the use of HAART, problem drinking, age, race, income, education, illness duration, study site, and baseline virological and immunological indicators (Cook et al., 2008). In terms of opportunistic infections, Cook and colleagues (2008) found that persistent and intermittent crack users were more likely than non crack users to develop opportunistic infections. Mientjes, Vanameijden, Vandenhock and Coutinho (1992) found similar results in a cohort of drug users in Amsterdam, in that, the risk of bacterial pneumonia was considerably more in HIV infected drug users compared to HIV infected nondrug users. Selwyn, Alcabes, Hartel, Buno, Schoenbaum, et al., (1992) looked at the clinical manifestations of HIV in people who used injection drugs and people who did not use injection drugs and found that injection drug user's progress to AIDS was at comparable rates to non-drug users. However, Selwyn and colleagues (1992) found that injection drug users had substantial

pre-AIDS morbidity and mortality, most notably from bacterial infections, as compared to nondrug users.

Trust in their healthcare provider. The trust that participants had in their healthcare providers stemmed from an innate confidence that their health care provider was telling the truth, in that HAART was needed to stay alive. Participant 006 remarked that HAART was her lifeline and that her healthcare provider was 100% responsible for giving her this information. Participant 005 spoke of how her healthcare provider constantly conveyed a steady message, which was to continually stress the importance of HAART and how HAART would only continue to work if she made it part of her life. The common opinion of having a trustworthy healthcare provider by the participants was summarized by Participant 009, when he stated that he was sure that his health care providers were telling him to take HAART because it works, and that the healthy changes he felt in his body were evidence enough for him to continue taking HAART. The participants reported that by trusting the advice of their health care providers, it allowed them to overcome a lack of knowledge about the side effects and long-term implications of HAART.

A review of the literature found evidence to support the participants' claims that a trustworthy healthcare provider is essential in maximizing adherence to HAART. A study by Watt et al. (2009) found that research participants all reported and appreciated the information they received on taking HAART and the openness of staff in addressing their problems proved helpful in committing to, and sustaining adherence to HAART. Additionally, Alfonso, Geller, Bermbach, Drummond and Montaner interviewed 20 patients on HAART at an urban outpatient infectious disease clinic and found that medical professionals were integral to the successful adherence to HAART (2006). Alfonso and colleagues showed that patients' confidence in the

care they received and their belief that they received a high level of expertise was critical to maintaining their commitment to adhere to HAART (2006). What's more, the research participants stated that it was easier to adhere when care providers were accessible, available and when they felt genuinely liked by their care providers (Alfonso et al., 2006).

The literature on trust among Aboriginal people and healthcare providers is limited, but a connection to the effects of colonization and the resulting mistrust of not only healthcare providers but all of Western society must be understood. Pointers on how healthcare providers could build trust with Aboriginal people were found in the literature, including the offering of traditional health and wellness programs within conventional healthcare services (London, LeBlanc & Aneshensel, 1998). Jackson and Reimer found that Aboriginal people often wished to be more involved in decision making about treatment options, and wanted to feel that healthcare providers spent a sufficient amount of time with them to accurately communicate treatment information (2005). Aboriginal people also valued the option of deciding how much involvement they had in health decisions, in that, at times they wanted the healthcare provider to make all the decisions and at other times they wanted to make the decisions (Jackson & Reimer, 2005). Finally, in terms of HIV specific care, a strong relationship and recognition of the healthcare provider was able to provide sensitive and clear information (Marelich, Johnston-Roberts, Murphy & Callari, 2002).

Daily routines. In terms successful adherence to HAART, five of the participants considered it vital to have developed a routine that incorporated taking a pill into their everyday lives. When asked to elaborate on their routine, two of the participants commented on the length of time that it took to remember to take HAART daily. More in depth answers were offered by three participants who were eventually able to remember to take HAART every day, not simply because they tried to remember, but because they focused on making HAART part of their daily routine Participant 008 spoke of a morning routine that she tried to follow. This routine consists of wake up, eat breakfast and take her pills in the same order every day. Participant 005 spoke of how she consistently reminded herself that taking HAART was just like washing her face or getting dressed — something she did every day. Participant 004 stated that her routine was not one solely of her own design, but also of her nurse who would drive by her place every morning on his way to work to remind her to take her pills. She stated that, "I knew he cared for me and that's what helped me care for myself." The building and maintaining of a regular routine was a common struggle of the participants in this study, each with a differing degree of success. Factors which may be contributing to the difficulties in establishing a regular routine include the chaotic life that many of the participants were living. A chaotic life which can include unstable housing, associated morbidities of addiction, other health issues, intergenerational affects of colonization, residential schools and the resulting marginalization, intergenerational affects of people of Canada live with today - to name a few.

The participants in this study who were the most successful at remembering to take HAART have successfully incorporated the act of taking their pills into everyday life routines The success the research participants found in using routines is supported by the academic literature. However, the literature also points to the limitations of relying excessively on routine Watt et al. (2009) found people on HAART who anchored the time of taking their pills with other regular activities. - such as meal or tea times, brushing their teeth, prayer, or radio and television programs - were more successful in achieving the high levels of adherence required for maximum viral suppression. On the contrary, the limitation of relying on routines was discussed by Golin and colleagues (2002) who reported on a study that participants found it hard to integrate HAART into their daily routines. They found that more than two thirds of the participants reported that their most basic daily activities could act as a barrier to taking HAART and those participants had to balance their needs of sleep, eating, working, and social activities against the possible side effects of HAART, the storage requirements of HAART, and the food requirements of HAART (Golin et al., 2002). Furthermore, approximately one quarter of the participants stated that when their routine changed even minimally, it was much harder to remember to take HAART (Golin et al., 2002). A study by Beusterien, Davis, Flood, Howard and Jordan (2008) asked 35 people on HAART what factors were involved in adherence. One of the main themes to emerge was the lifestyle fit of HAART. In other words, how well HAART fit into a person's life was just as important as how well a person could adapt their lifestyle to fit the "inflexibility" of HAART. To clarify, Vervoort, Grypdonek, de Grauwe, Hoepelman, and Borleffs (2009) found that when HIV was accepted into a person's self-identity, that the taking of HAART could become a routine, and that the more a person accepted HIV and internalized HAART as part of his life, the more automatic adherence became.

The concept of the "inflexibility" of HAART was mentioned by several participants who expressed feelings of being "burdened" by the knowledge of being forever bonded to HAART, in that to be healthy, one must be adherent, but to be adherent, one must place HAART as a top priority in life. Therefore, in order for HAART to be successful, it must, by necessity, outrank several quality of life activities, such as traveling, visiting friends, and making random spur-of-the-moment decisions. At times however, HAART is known to have many potential side effects ranging from nausea to life threatening conditions that can greatly affect a person's desire to continue taking HAART. The impact of these side effects on adherence to HAART has mixed

reviews. Watt and colleagues (2009) found that the side effects noticed – predominately gastrointestinal – were considered minimal to participants' overall health gains and did not influence adherence. Furthermore, in the study done in India, the idea of side effects having the potential to influence adherence was not identified by any of the research participants (Kumarasamy et al., 2005). However, a study done in South Africa found that feeling healthy from taking HAART was not always a strong enough incentive to override the negative side effects of HAART (Dahab, 2008). Dahab (2008) found that positive health gains promoted adherence, but that experiencing side effects was a barrier strong enough to cause discontinuation of HAART.

In this study, despite the severity of the side effects reported by the research participants, none of the participants reported that the side effects of HAART were a contributing factor in missing doses of HAART. Participant 001 reported that the central nervous system side effects that she dealt with were "violent" dreams that were full of "blood, guts and killings", and that the dreams were so vivid that at times she woke up at night crying. Participant 009 felt he "almost died" from the side effects when he first started HAART – referring to nausea, vomiting, diarrhoea, photo-sensitivity, blackouts and achy joints that persisted for the first several months of starting HAART. Participant 008 spoke of the frustrations caused by HAART side effects, but made no mention of considering stopping HAART. The sentiment of the participants perspective on why they persevered was punctuated by Participant 006 and Participant 009 when they said, "I'd rather take my pills and be nauseous and live than not take it," and,

I just kept telling myself that okay, you know what, I'm doing this for the right reason. I'm um, doing this because it's going to prolong my life. I'm, you know what, okay so I'm hurtin' right now, but you know what, I'm going to live longer... 64

Support from AIDS service organizations, family and friends. The next most common support identified by the participants is the support they received from AIDS service organizations (ASO), family and friends. Examples of support were plentiful and included but were not limited to the provision of a steady relationship, food hamper programs, gentle reminders to take HAART, rides to the pharmacy, and most importantly, the knowledge that someone cared for them. These examples were very similar to what Watt et al. (2009) found to be effective social assistance strategies to encourage adherence to HAART which included: explicit reminders to take HAART, receiving material support which included money and food, and emotional support. Alfonso and colleagues (2006) found that participants with high levels of adherence appreciated when family and friends assisted with decision making and provided help with daily living. More specifically, Alfonso and colleagues (2006) found that family and friends provided a sense of structure and normalcy to daily routines and that the participants expressed that having someone to talk to, who accepted and appreciated them for who they were, were critical to adherence success.

The Aboriginal literature reported similar findings with that of the research participants in terms of the benefits of support from ASO, family and friends. Mill, Keenan, Lambert, Larking and Ward (2006) conducted 31 interviews with Aboriginal people living with HIV in Alberta, Canada to discuss their experiences living with HIV. They found that strong support systems were needed following diagnosis, and that support services needed to be ongoing to ensure that people in different stages of acceptance of their HIV diagnosis could access services when ready (Mill et al., 2006). Participants described the support they received from family and friends as a source of finding purpose in life, and of getting the courage to live 'strongly' with HIV (Mill et al., 2006). Jackson and Reimer (2005) found that 157 (80.5%) of interviewees used AIDS service

organizations. Furthermore, Jackson and Reimer found that 147 (74%) of interviewees stated that they had had positive experiences with AIDS service organizations. Reasons for attending ASO's included the ability to share their stories, to get information about HIV, to receive emotional support, and to receive support from peers (Jackson & Reimer, 2005). On the flip side, Jackson and Reimer also reported that 49 (25%) of interviewees reported concerns about ASO's. These concerns included confidentially and privacy issues, logistic barriers, and lack of knowledge of existing ASO's (2005).

Barriers to taking HAART. When asked to identify, "What makes it hard for you to take HAART?" the two main themes that emerged were *being high* and the *physical location* of the HAART medication.

Being high. When asked, "How does being high affect your ability to take your HIV medications (adherence)?" the most common answer given by six of the respondents was that being high made it harder for them to take their antiretroviral medications. Only two participants identified that being high did not affect their ability to take HAART. The three main reasons that summarized how being high affected the participants' ability to take their HAART were: changes in priorities, forgetfulness, and losing track of time when using injection drugs. Participant 008 stated that when using illicit drugs heavily, the drugs became the most important thing in her life – more important than family, than HAART, than food and water. Participant 005 stated that when using heavily, her morning priority was to secure her drugs for the day, and that she focused her attention on 'hustling' and whatever 'scam' she needed to do to get money to buy drugs, and that it was only after she had her drugs that she was willing take her ARVs – if she could remember. Two of the clients spoke of "forgetting" to take HAART, even though they
were on methadone as well. Participant 001 stated that when she gets high on cocaine³³, she will stay high for days without sleep, and that when she does go to sleep she will sleep for two to three days and then wake up "dope-sick"³⁴. She will then need to get more drugs, which will result in her missing her doctor's appointment, and she will not go to the pharmacy for her methadone or HAART. Participant 006, stated that being high will make her forget to take her medications, or not remember if she took them, and that she would eventually get to the pharmacy for her methadone, but maybe not on the same day. Participant 008, who is very proud of her ability to take her pills, remarked that being high will sometimes cause her to forget if she took them or not, and that the forgetfulness will cause her to break routine. Two participants spoke of how time just "slips by" when they are using drugs. Participant 004, stated "…time passes that you don't realize has even gone by when you're, when you're on whatever." This sentiment was echoed by Participant 009, who stated,

I take [HAART]..., but usually I'm either late or like....way, way, late but I'll still take them. And then I'm kicking myself going oh, damn, you know what, I missed my time.... And then there's times when I just forget altogether even though I've been thinking about it for a few hours.

Participant 006 summed up the sentiment of participants feelings on the subject of forgetfulness when she stated, "Being on a run and forgetting to take them. I can remember to do a fix but I can't remember to take my meds, you know?"

There is a complete lack of literature examining Aboriginal specific reasons for how being high can act as a barrier to taking HAART. What can be said, and is drawn from the

³³ Cocaine is a powerfully addictive stimulant drug. Cocaine can be snorted or dissolved in water and then injected. Cocaine constricts blood vessels, dilates pupils, and increases body temperature, hear rate, and blood pressure. It can also cause headaches and gastrointestinal complications such as abdominal pain and nausea. http://drugabuse.gov/infotacts/cocaine.html

³⁴ Dope sick refers to a person who is physically and mentally sick because they are coming off of heroin http://www.urbandictionary.com/define.php?term=dope%20sick

existing literature, is that "forgetfulness" is a critical and valid reason that explained why people do not take HAART 100 percent of the time. In 2004, Kerr and colleagues interviewed 108 people who inject drugs in Vancouver. They hoped to discover reasons why people who inject drugs are less likely to take HAART as effectively as people who do not inject drugs. The study found that seventy-one (66%) of the 108 participants were less than 95% adherent, and the number one reason for missing HAART was forgetting (Kerr et al., 2004). In Jamaica, Harvey, Carrington, Duncan, Figueroa, Hirschorn, et al. (2008) studied HAART adherence factors in 116 adults and found that 43 (37%) of the participants cited that forgetfulness was one of the main reasons for not taking HAART. Furthermore, a study by Tucker, Orlando, Burnam, Sherbourne, Kung and Gifford (2004) examined data of 1,889 patients on HAART from the HIV Cost and Services Utilization Study, and found that the difficulties associated with remembering to take HAART was one of the major factors that contributed to non-adherence for drug users.

The reasoning of why participants forget to take HAART can be attributed to actual drug highs, but additional deliberation must be considered when examining the characteristics of this study's research participants. Participants in this study were highly marginalized and often had competing priorities for their attention, such as obtaining shelter, food security, personal security, and security of belongings. These factors – when combined with the quest to obtain injectable drugs to get high – often meant that achieving high rates of adherence to HAART was nearly impossible.

The two participants who responded that injection drug use does not affect their HIV treatment believed that they have been able to separate their lives as injection drug users and that of people living with HIV. Participant 003 summed up this perspective when she explained that she understood that illicit drugs would always be available, but that her HIV medication had the

potential to develop resistance and not work anymore, so she needed to make it a priority in her life. However, the existing literature, as discussed earlier in this paper, would suggest that these participants have been more able to fully integrate HIV into their personal identities and therefore are better able to internalize and comprehend the importance of making HAART a priority in their lives, over that of injection drug use.

Physical location of HAART. The physical location of HAART, as a barrier to strong adherence, was mentioned by four participants. Three of the five participants who were on methadone expressed difficulties in having HAART attached to the daily witnessed methadone program. Participant 001 described the issues of the methadone daily witness program³⁵ when she stated, "It gets stressful having to go in every single day to the pharmacy." Other participants noted the barrier to having their HAART at local pharmacies was the restrictions put on by pharmacies for medication pick-up –i.e. limited hours of business – that made it difficult to get their methadone and HAART. One client, who at the time of interview was homeless, spoke of having to keep her IIAART in her bag and how that created difficulties because she has no safe place to store her medications.

A study by Stein and colleagues examined HAART adherence rates for methadone patients on HAART. The study found that methadone patients who continued to use injection drugs were significantly more likely to be non-adherent than non-injecting methadone patients (2000). Moreover, a vast amount of literature can be found to support the argument that being on methadone acts to increase overall adherence rates to HAART. A study by Uhlmann, Milloy,

³⁵ Daily witnessed methadone ingestion is when a patient who is prescribed methadone must attend a pharmacy everyday to receive their dose of methadone. The pharmacist must assess the patient prior to providing methadone to the patient. After the patient drinks the methadone, a short conversation is required to ensure that the methadone has been swallowed. Confirmation that the methadone is swallowed is necessary as some patients may try to keep the methadone in their mouth until they can spit it into a container in order to sell. http://www.bcpharmacists.org/libraiy/H-Resources/H-4_Phaimacy_Resources/5059-Methadone. Maintenance. Guide.pdf

Kerr, Zhang, Guillemi, Marsh, et al. (2010) found that methadone maintenance therapy contributed to faster initiation and ensuing adherence to HAART among people who were living with HIV and who were engaged in opiate-based injection drug use. Raffa, Grebely, Tossonian, Wong, Viljoen, and colleagues (2007) looked at 60 patients enrolled in a community supported pharmacy methadone program who were also receiving daily witnessed HAART. Of the 60 patients, only 4 (6.7%) abstained from illicit drug use for the duration of the study and the study adherence rate was 84.5%. Conway, Prasad, Reynolds, Farley, Jones, et al. (2004) conducted a study that evaluated the use of directly observed therapy (DOT) for the management of HAART for patients in a methadone program. The study enrolled 54 patients, of which, 48 (89%) continued to actively use injection drugs throughout the study period. The study results indicated that 34 (65%) of participants achieved HIV viral suppression at the two year follow-up. The study showed that DOT can be successful for even the most difficult to treat – a category that people who use injection drugs fit into (Conway et al., 2004).

In terms of Aboriginal people, there is a scarcity of evidence in Canada examining the effectiveness of methadone maintenance therapy for Aboriginal people who are opiate-dependent and living with HIV. Oviedo, Guh, Marsh, Brissette, Nosyk, and colleagues (2010) examined the characteristics and responses to treatment among 192 (60 Aboriginal) people receiving heroin-assisted treatment in the North American Opiate Maintenance Initiative (NAOMI study). The HIV rates at baseline showed that 23.3% of the Aboriginal participants had HIV, compared to 8.3% in the non-Aboriginal group. Participants were divided into two groups; one received injectable hydromorphone or diacetylmorphine, and the other received oral methadone. The results showed that at 12 months, the retention rates were 84.4% in the injectable hydromorphone/diacetylmorphine group and 57.1% in the oral methadone group (Oviedo et al.,

2010). The authors concluded that offering medically prescribed diacetylmorphine or hydromorphone to Aboriginal people with long-term opiate dependence could be an effective means of attracting and retaining this target group in addiction treatment, and thus reduce the risk of HIV infection, and facilitate the provision of antiretroviral treatment for those already infected (Oviedo et al., 2010).

With respect to the concerns expressed by the participants about the perceived stress and added difficulty of attending daily witnessed methadone programs. Along with the supportive literature that details the benefits of daily witnessed treatment. The participants in this study that were engaged in a methadone program, on average, had a greater suppressed viral load than participants who were not on methadone maintenance therapy. This indicator was strongly suggestive of higher average HAART adherence rates. That said, although the evidence in the literature and the viral load levels of the participants suggested that HAART given in association with methadone maintenance therapy was more successful in promoting adherence, respect must be given to the enormous amount of energy and time that it takes for the participants to visit a pharmacy daily for medication dispensing. This leads to the idea of medication burnout³⁶ and the conscious decision to stop taking HAART as health is regained and more "normal" lives are established that begin to conflict with the commitment needed for high adherence, as referred to by Ware et al. (2006).

Making supports for HIV treatment work better. When asked what improvements could be made to existing HAART adherence support, the most common answer given was that healthcare providers need to be *more caring* in the treatment of Aboriginal people living with HIV.

³⁶ Pill fatigue refers to a condition that may occur over time in chronically ill patients who have to take a lot of medication, in which the patient stops taking pills because of the stress and monotony of constant pill swallowing http://www.urbandictionary.com/define.php?term=pill%20fatigue

More caring. The resounding answer, when asked how HIV treatment could work better for participants, was that healthcare providers need to be more caring. When probed to elaborate on the definition of "more caring" the participants' responses revealed two main themes. Firstly, that healthcare providers need to be more patient-centered. For example, health care providers need to see that the person sitting in front of them is a "human being", who happens to be Aboriginal, who lives with HIV and who uses injection drugs. Secondly, healthcare providers also need to be more consistent in terms of day-to-day interactions and confidentiality. The need for healthcare providers to recognize the person, and not simply the diagnosis, was succinctly described by Participant 008, when she stated,

It doesn't matter what he is, a dealer, user, it doesn't matter what he is, he's a human being. You should take away everything except the fact that he's a human being.

And leave everything else to go. And that's just the way it should be. She further elaborated that healthcare providers need to "drop the stereotypes" that are often associated with people who use drugs and not worry so much about the drugs they are doing, how much money they have or other negative undertones, and focus on the reason that the healthcare visit is taking place. The idea of treating the human being and not the addict was further discussed by Participant 005, who commented on the strength of her health care provider and his ability to see the human being behind her often chaotic presentation,

He showed true concern for me. I'm a human being and a person. Not as being

Aboriginal or being white, or anything else, just as being, a person and helping save me and how strong I became because of the love that was shown.

Another participant expressed that a provider who showed interest in the client's family and life issues outside of HIV and drug use was a perfect example of a caring provider. Moreover, many participants remarked that the more a provider showed that they actually cared about them, the more likely the participants were to care about themselves, and the more likely they were to start taking their HIV medications.

The idea of greater consistency and awareness of confidentially was also expressed as a way of showing a more caring approach. Consistency in the relationship was seen as a caring act, and to paraphrase the participants' perspective: consistency is not reflective of someone who is only doing the job to collect a pay-cheque. Furthermore, many of the participants remarked that healthcare providers should not assume that clients are open about their HIV status and that even in healthcare settings such as hospitals and clinics, healthcare providers should ask permission to talk about a patient's health condition –i.e. HIV – to other healthcare providers need to be asked in a positive manner, and more as a question rather than a directive, because being authoritative is not a good way to earn patient trust and facilitate cooperation in health care plans.

The views expressed by the research participants were shared in the existing literature. Many examples of the effectiveness of a more client centered-approach could be found. A study by Beach, Keruly and Moore (2006) involving 1,743 people living with HIV, examined whether patient-provider relationships were associated with better adherence and health outcomes for patients with HIV. The study found that patients who reported that their healthcare providers knew them as individuals had higher adherence rates to HAART than those who felt distant from their healthcare providers. Likewise, Roberts (2002) interviewed 28 people living with HIV regarding the physician-patient relationship and its connection to HAART adherence. The results showed that good quality physician-patient relationships tended to promote adherence while lesser quality relationships impeded it. A study looking at the adherence rates of 137 AfricanAmericans who used crack-cocaine found that when a patient believed his healthcare provider practiced with a patient-centered approach, it infused hope and optimism in the patient, and ultimately increased adherence rates (Atkinson, Schhonnesson, Williams, & Timpson, 2008). A study by Stall and colleagues (1996) on the decision to accept and start HAART by gay and bisexual men identified that the way the message was conveyed by healthcare professionals about the importance of engaging in HAART was crucial to achieving high adherence rates. Additionally, Ungvarski found that certain characteristics and personality attributes of the healthcare provider were important in HAART therapy (1998). Finally, a study involving 47 HIV positive gay men found that healthcare providers who were sensitive to their patients needs were more likely to encourage care seeking behaviours inclusive of better adherence to HAART (Schneider, Kaplan, Greenfield, Li & Wilson, 2004).

In terms of Aboriginal specific literature, it is important for the healthcare provider to be conscious of the fact that one of the major consequences of colonization was the mistrust by Aboriginal people towards governments and health organizations, and that this mistrust resulted in many Aboriginal people not using these services for diagnosis and treatment (Jackson & Reimer, 2005; Williams & Guilmette, 2001). For this reason, it is important for healthcare providers to approach HIV care from a culturally sensitive position that works on building a relationship. CAAN (2008) found that using a "relational care" approach enabled healthcare providers to build the needed relationships to effect positive change in the health status of Aboriginal people living with HIV. Relational care begins with the core elements of trust, rapport, respect for individuality, consideration for Aboriginal and holistic approaches to well-being, flexibility and openness toward alternative, complementary and integrated care strategies (CAAN, 2008). Furthermore, a willingness by healthcare providers to surrender expert status

earned by their education and by gaining knowledge of how better to meet the needs of Aboriginal people living with HIV works towards minimizing further harm (CAAN, 2008). Relational care encompasses the physical, social, emotional, spiritual dimensions of human connection (CAAN, 2008). A physical connection can be established through creating a warm and Aboriginal friendly environment, and can be seen through kindness expressed in the body language used by healthcare providers (CAAN, 2008). Social connections are made by acknowledging humans place in the physical world and by showing respect for the power and privilege healthcare providers have. Social connections can be further nurtured by acknowledging the place we – humans –occupy in the world and the power and privilege that comes from our race, gender, language and sexuality. Social connection is furthered strengthened when we work towards a common goal of wellness for Aboriginal people (CAAN, 2008). Listening, sharing and sense of family make up the emotional connection of relational care (CAAN, 2008). Finally, spiritual connection embraced notions of acceptance, open-mindedness and human competence. It celebrates the diversity of Aboriginal people living with HIV in terms of cultural background, personal experience and sexual orientation (CAAN, 2008). The core elements of relational care include trust; rapport; respect for individuality; regard for Aboriginal and holistic approaches to well-being; flexibility and openness toward alternative, complementary, and integrated care strategies; and willingness by healthcare providers to surrender expert status earned by their education to learn about how to better meet the needs of Aboriginal people living with HIV (CAAN, 2008).

Aboriginal Traditions.

One of the purposes of this research was to ascertain the role that Aboriginal traditions have in the lives of each participant, and how this role is used to influence HAART adherence. The most common answer given by the research participants when asked about Aboriginal traditions was that they do not know anything about Aboriginal traditions, and therefore, Aboriginal traditions were not part of their lives. Furthermore, when asked if the participants felt a desire to "reconnect" to Aboriginal traditions, only three of the participants responded positively and continued to talk on the subject of Aboriginal traditions, while the other participants responded with answers that moved away from the topic of Aboriginal traditions.

Reconnection to Aboriginal traditions. When asked to tell the story of Aboriginal traditions in their lives, three of the participants responded that they considered Aboriginal traditions an important component of health in their lives, but that their knowledge of Aboriginal traditions was poor. Evidence of the lack of traditional knowledge can be drawn from comments made by each participant. Participant 009 openly stated that he knew very little of his past, to the point of calling himself a "White Indian". He spoke about wanting to learn about smudging, traditional sweats, and medicines. Participant 008 commented that she wanted to be like her mom someday – a woman who actively practiced traditional ways of life. However, she implied her lack of knowledge by saying that she would need to start spending more time learning from her mother because she had a "long way to go," as her addiction still held her in a strong grip. Encouragingly, she also recognized a change in her life-focus as she stated, "My focus used to be who's got the best drugs, you know, but now my focus is where can we go to this, this and this and where is the best moose hunting. I guess it's a personal choice." Participant 006 spoke of the recognition of storytelling, and how she hoped to one day help people get healthy by sharing her life story of being an Aboriginal woman living with HIV and using injection drugs.

The superficiality of the sentiments expressed by Participants 009, 008 and 006 in terms of their self proclaimed naiveté of Aboriginal traditions, coupled with the absence of responses

from the other participants, may suggest that a disconnect from traditional culture and identity exists within the participants. It could be hypothesized that due to this disconnect, a further divide of not expressing interest to reconnect was made by the other research participants. It could also be put forward that this absence of expressed interest was driven by a lack of knowledge of how Aboriginal traditions could help in creating one's identity and achieving increased health status.

The academic literature clearly articulates that the residual effects that colonization has had on the Aboriginal people of Canada – such as residential schools, intergenerational trauma, marginalization, violence, addiction, absolute poverty, and racism – have all had a dramatic psychological impact on the well-being of each and every Aboriginal person in Canada (Taylor & Usborne, 2010). Moreover, it cannot be refuted that the lasting effects of colonization has fundamentality changed the traditional culture and identity of Aboriginal people, and therefore impacted the cultural identity of each individual (Taylor & Usborne, 2010). In terms of Aboriginal people living with HIV, CAAN (2008), found that approximately half of Aboriginal people living with HIV who were interviewed shared a sense of disconnection from their Aboriginal culture. Reasons for this disconnection may include: being fostered or adopted into non-Aboriginal families; living through residential schools; traumatic experiences of stigma, homophobia, ostracism, and abusive relationships due to being HIV positive; and lack of support services in home communities, resulting in the need to move to receive HIV care. Evidence of "disconnection" from Aboriginal culture and a shift in "identity" is reflected by Participant 008,

I think that because of, and I know that people hear this a lot, but nowadays the way we were raised, who we are, I was raised to be a drug dealer. I was raised around, like I remember watching people shoot up when I was 10 or 11 years old. I was 77

raised in this environment and every Aboriginal family I know, every person I talk to was also raised in this environment, around alcohol, drugs and violence. So how do you fix something that has been ingrained in you since you were a baby? So that's what they need to figure out, is how can we reprogram an entire race of people. It's pretty much. And I've been thinking about it and I sit at home and think about it and I don't know. The only thing that works for me is like I said my mom. Like she's an old traditional woman, she was raised in the bush and I have enough respect for her that I will stay clean over the summer and bring her berry picking and do all these things she needs to do because I have that respect for her but 90% of us haven't got that respect anymore. We've lost it.

A review of the existing literature of self perception tells us that identity informs people of who they are, to whom and where they belong, of which practices define them, of what their individual purposes and roles are in life, and of how each person is distinctive from others (Kirmayer, Brass & Tait, 2000). Furthermore, Kirmayer and colleagues found that identity is continually reinforced through key practices and social institutions (2000). Ashmore, Deaux, and McLaughlin-Volpe (2004) found that groups to which people belong to, influence identity, in that, culture, religion, social-class, economic-status, gender, profession, and recreational groups all may contribute to an individual's identity.

In terms of Aboriginal people, Karlsen and Nazroo (2002) found that strong connections to cultural and ethnic identity among Aboriginal people could at times override the negative stereotypes of poverty and discrimination – two conditions which many Aboriginal people live with. Furthermore, Karlsen and Nazroo found that the symbols and relationships attached to understanding ethnic identification could be powerful in promoting better health (2002).

Additionally, Walters and Simoni (2002) found evidence supporting that the more individuals learn about and connect with their traditional culture, the stronger their coping abilities in dealing with negative encounters and events - like living with HIV. Finally, CAAN (2008) found that participants believed that by reconnecting with their culture, they were able to seek new meaning in life, learn to take pride in being Aboriginal, and to generally improve their self-esteem. In terms of this study, it is important to acknowledge that Participant 009 identified Aboriginal culture to that of being a drug dealer, when she inferred that the culture she was raised in raised her to be a drug dealer. Therefore although this participant self-identified a strong connection to her Aboriginal culture - albeit her interpretation of Aboriginal culture meant or included to be a drug dealer – attention must be given to what "is" Aboriginal culture. So not only does a reconnection to culture need to be facilitated, but for some, "Aboriginal culture" must also be redefined. When asked how a reconnection to Aboriginal culture could be facilitated, a number of answers emerged from the group. Participant 005 spoke about the importance of stable housing and how having a home needs to be formally identified as a priority for Aboriginal people living with HIV. Participant 009 spoke of his new dedication to visiting with an Elder and the wisdom and knowledge that could be gained. Participant 006 spoke of the need for peercounseling because she found it much easier to connect with other Aboriginal people living with HIV because of the innate connection she felt with people of Aboriginal descent who shared the burden of living with HIV and addiction issues. Participant 008 spoke in rich detail of how the reconnection to Aboriginal culture -for HIV positive IDUs - should be facilitated. She also spoke of how to motivate a reconnection for Aboriginal people who show little interest in Aboriginal ways-of-life. She spoke of the need to create a belief in Aboriginal people that they are just as important as everybody else, which would result in a greater sense of self-worth. This

in turn, would create greater opportunities for self-help and healthy living practices. Participant 004 commented that how she grew to embrace HAART was reflective of this approach, as she stated that the main reason she became adherent to HAART was because she realized her nurse truly cared for her, and his "caring" resulted in her "caring" for herself and the decision to take HAART.

The literature tells us that all the ideas of how to reconnect to culture offered by participants are valid and supported. Cisneros (2007) completed a literature review on the relationship between housing and HIV status. He found that having a stable place to live influenced the length and quality of life itself. Turton (1997) described the ways of knowing about health from an Ojibwe perspective. She reported that Elder teachings were highly respected because knowledge in Aboriginal communities was not passed through books or videos, but rather oral tradition. Harris and Larsen (2006) interviewed 12 people living with HIV who had experience with peer counseling. The study found that peer counseling provided benefits to both parties. These benefits included seeing what is possible in life while living with HIV, and finding a greater sense of meaning and purpose in life. Marino, Simoni, and Silverstein (2007) conducted interviews with nine HIV positive-peer counsellors to examine if the peers themselves benefited from being peers. The study found that the peers identified three main areas that they benefited in. Firstly, they reported a reduction in the sense of isolation experienced or related to in living with HIV. Secondly, the peers reported a sense of being counselled themselves, which was viewed as beneficial. Thirdly, the peers reported a sense of empowerment and confidence when dealing with their healthcare providers. Mill, Keenan, Lambert, Larkin and Ward (2008) interviewed 31 Aboriginal people living with HIV and found that strong community supports was key in living successfully with HIV. Richmond, Ross and Egeland

(2007) examined the importance of social support in promoting health in Aboriginal Canadians. The study grouped social supports into four broad categories: positive interactions, which referred to spending time with others; emotional support, which referred to guidance and feedback; tangible support, which referred to actions, including getting rides to appointments; and affection and intimacy, which referred to caring, love and empathy. The study found that having social support was a strong determinant of health (Richmond et al., 2007).

Conclusion

This chapter examined three broad topics using Grounded Theory: living with HIV and injection drug use; HIV treatment; and HIV, IDU, and being Aboriginal. Many points expressed by the research participants mirrored what could be found in the existing literature.

The points that differed or were experienced differently by the participants in this study in terms of HAART enablers, as compared to existing literature, included *trust in healthcare providers*, and the establishment of *daily routines* to facilitate HAART adherence. *Trust in healthcare providers* was inherently much more difficult to achieve for Aboriginal people due the lingering effects of colonization. *Daily routines* were important, but the additional difficulties of addiction, homelessness, intergenerational affects of colonization, marginalization, intergenerational trauma, violence, food insecurities, the inability to find meaningful work, and societal exile that Aboriginal people of Canada live with today, greatly inhibited the ability of the participants to establish long-term routines.

The points that differed or were experienced differently by the participants in this study in terms of barriers to HAART adherence, as compared to existing literature, were identified in the *being high* discussion. The existing literature supports the statement that *being high* promotes a greater level of forgetfulness in people, resulting in missed HAART. The differences identified by this study were that not only did the participants face the concept of 'forgetfulness,' but that the participants were highly marginalized and had competing priorities including obtaining shelter, food, and personal security – all of which contributed to 'forgetfulness' of taking HAART.

Other points that differed or were experienced differently by the participants in this study in terms of how adherence supports could be improved, as compared to existing literature, were minimal, but were identified in the *more caring* section. It was found that due to the effects of colonization, an inherent mistrust of healthcare services exists within Aboriginal communities, and that culturally specific actions must be undertaken to create an environment that demonstrates *more caring and consistency*. This action could be undertaken by using a 'relational care' approach, as detailed earlier.

Finally, the disconnection to Aboriginal culture, and its effects on adherence and participation in healthcare was discussed. No major difference was found among the study group and the existing literature. However, this section did further explore a gaping hole in the provision of healthcare, namely the lack of a relational care approach by healthcare providers. It also provided great insight into potential actions that could be taken to foster a greater level of healthcare uptake among Aboriginal people living with HIV and injection drug use. As it can be argued that in general the participants are living more for "survival" and that the basics of food, shelter, and access to health care are more pertinent to their day to day lives then fostering a reconnection to Aboriginal culture. Moreover, consideration was given to the idea that many of the participants lacked a clear understanding of what constitutes Aboriginal culture. Therefore not only does the healthcare provider have a duty to provide "relational care" but also a duty to foster a more accurate understanding of Aboriginal culture.

Chapter Six: Summary, Conclusions, and Implications

Summary of the Research Study

Adherence to Highly Active Antiretroviral Treatment is very demanding and requires high compliance rates - over 95% - to achieve maximal HIV viral suppression, resulting in optimal health gains. The purpose of this study was to elicit an understanding of how Aboriginal people on HAART, who currently use illicit injection drugs, achieve the necessary high adherence rates required of HAART in hopes of modifying the adherence support they receive from their healthcare providers. This study examined interview data from nine Aboriginal people living with HIV in Prince George, British Columbia, who are on HAART, and who use illicit injection drugs. A Grounded Theory methodology, as described by Creswell (2008), was used. Data interpretation was guided by Strauss and Corbin's (1998) three phase analysis strategy. Findings from this study revealed that *building trust*, and establishing *daily routines* among the research participants differs from what is found in the current academic literature. Secondly, this study found that while forgetfulness was a common theme for not taking HAART, the participants in this study had many competing priorities in addition to forgetting while being high, as compared to other populations discussed in the academic literature. Thirdly, in terms of what the participants wanted from adherence programs, it was found that the greatest expressed need was that healthcare providers be more *caring* and *consistent* in their approaches to healthcare. Finally, this project found evidence to support the concept that *disconnection from* Aboriginal culture, while a major theme among the participants, was not a main barrier to HAART adherence

Conclusion

In this study, nine Aboriginal people told their stories of the struggles they experienced living with HIV and injection drug use, while still experiencing the intergenerational effects of colonization. Each participant opened his or her heart and soul and expressed to the best of their abilities what they felt was needed to help assist them through their journey. It is hoped that the lessons learned from this research can influence the care practices of healthcare providers who support Aboriginal people living with HIV.

The key points identified in this study include the greater need for a more caring and consistent approach from care providers. That is, we must strip away our bias of what we see in front of us, and truly recognize that people living with HIV, addiction issues, mental health issues, legal issues, etc...are human beings first and foremost - possessing all the same feelings and rights that we have. We must continue to recognize that the lingering effects of colonization are still prevalent in Aboriginal societies and continue to pose great barriers to each and every Aboriginal person - especially those who are highly marginalized. Finally, we must advocate for greater connection to Aboriginal culture for those who wish to reconnect to a traditional way of life by not only encouraging that reconnection, but by actually fostering it to happen. The use of "relational care" teachings and the learning of "culturally safe" modalities can help bridge this void and help facilitate a greater understanding of the relationships and workings of traditional practices and Western healthcare.

Recommendations

Three major recommendations can be made of the findings from this study. One: promote reconnection to Aboriginal culture. Two: healthcare providers need to adapt a more holistic view of healthcare practices. Three: when designing healthcare related interventions for Aboriginal people living with HIV, attention must be paid to the basic necessities of life – personal safety, food, shelter, family, self-esteem, and love.

Promoting the reconnection to Aboriginal culture. Testimony by the research participants and evidence from existing academic literature provides support for the theory that the more a person learns about, and connects with his traditional culture, the stronger his ability to deal with negative health situations (Walters & Simoni, 2002). However, it is vital to remember that before a reconnection to Aboriginal culture can be facilitated, a redefining of what Aboriginal culture "is" may need to be done. Reconnection to culture can be facilitated by providing traditional services alongside Western medicine. This means that Western-trained healthcare providers need to work side-by-side with traditional healers and Elders, and health-clinics and programs for Aboriginal people need to be staffed by Aboriginal people. Additionally, non-Aboriginal staff members need to embrace traditional practices and learn how to incorporate tradition into their practices.

Holistic view of healthcare practices. According to traditional beliefs, all four elements of life are vital to health – physical, emotional, mental, and spiritual (McLeod, 2004). The four elements of life are elaborately entwined, and interact to support a strong and healthy person. If one of the elements is either neglected or given too much attention, wellness or balance suffers in all four areas, thus healing in one element can impact healing in another element (McLeod, 2004). However, Western medicine does not typically take into account this connection and tends to focus on each element individually. The ideas expressed in this project by the research participants are that healthcare providers need to be more caring, and recognize the individual and not just the disease. For this reason, it is imperative that healthcare providers recognize the value of a more holistic approach. A relational care approach that is recommended by the Canadian Aboriginal AIDS Network (CAAN; 2008) is a starting point that can help in building the necessary trusting relationships and allegiances between Aboriginal people and healthcare providers. Relational care involves two main themes: connecting and relationships. Connecting refers to the perception that a safe environment exists where Aboriginal people feel cared for as a person, not as a disease (CAAN, 2008). Relationships are conceptualized as the way healthcare providers interact with Aboriginal people, how they negotiate care, and how that care is individualized (CAAN, 2008).

Designing healthcare related interventions. Evidence provided by the research participants, which is supported in the academic literature, necessitates that program design pay close attention to cultural learning modalities, and that when crafting health related programs partnerships are built between Aboriginal and non-Aboriginal partners. When designing HIV related health programs for Aboriginal people, it is vitally important to understand Aboriginal world views and the fundamental differences between how Aboriginal and non-Aboriginal people perceive the effects of HIV. By offering a mixture of traditional health and wellness programs, combined with conventional healthcare services, it can ensure that Aboriginal people are more likely to participate in and sustain recommended care practices. Allies

Final thoughts

The results of this research project have had a profound effect on the writer's professional practice as a HIV nurse clinician. I have learnt how to slow down in my practice, to hear my client's stories and appreciate each client as an individual. I've realized that to be a nurse delivering high quality HIV care, I do not always need to speak to my clients about what it is like living with HIV or the issues they are having with HAART. The more I listen, the fewer

questions I need to ask, as answers to my thoughts tend to find their way to me through the stories I hear my clients tell.

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Appendix A Interview Questions

- 1. Please tell me your story of living with injection drug use?
- 2. Please tell me your story of living with HIV (and injection drug use)?
- 3. Please tell me your story of HIV treatment?
- 4. Please tell me your story of being Aboriginal, HIV positive and an injection drug user?

1 0000		[I	Injection Drug Use
1.0000				
	1.1000			Introduction to Injection Drug Use
		1.1100		-Peers
		1.1200		-Choices
		1.1300		-Environments (community)
	_	1.1400		-Trusted relationship
	1.2000			Role IDU Plays in Life
		1.2100		-Socio-economic status
		1.2200		-Family
	1.3000			Health outcomes of IDU
	1.4000			Triggers
		1.4100		-People
		1.4200		-Change in my emotional state
		1.4300		-Money in my pocket
		1.4400		-Offer of free drugs
		1.4500		-Media with addiction themes (movies, TV,
				etc)
		1.4600		-Geography (being near drugs)
		1.4700		-Lack of support
	1.5000			How I stay clean (free of drugs)
		1.5100		-Proper support structures
	_	1.5200		-The right people
	_	1.5300		-Knowledge of HIV disease process
		1.5400		-Marijuana
		1.5500		-Distraction (reading, exercise)
		1.5600		-Being by myself
		1.5700		-Aboriginal traditions
		1.5800		-Fear of overdose
	1.6000			Survival
2.0000				HIV
	2.1000			Living with HIV (and IDU)
		2.1100		-What it is like to have HIV
			2.1110	Fear
			2.1120	Anger
			2 1130	Always on my mind
			2 1140	Not on my mind everyday
		2 1200	2.1110	-Initial feelings of having HIV
		2.1200	2 1210	End of my life
			2.1210	Fear
			2.1220	
		2 1300	2.1230	Coning strategies Luse to live with HIV
		2.1300	2 1310	Talking to friends / sharing my story
			2.1310	Poflection
			2.1310 2.1320	Talking to friends / sharing my story Reflection

Appendix B Code book

			2.1330		Compartmentalizing
			2.1340		Using drugs and other risky behaviours
			2.1350		Living one day at a time
			2.1360		Community supports
			2.1370		Incorporating HIV into self perception
			2.1380		Taking care of myself
				2.1381	-Being aware of others
			2.1390		Recognizing potential triggers
		2.1400			-My place in the community living with HIV
		2.1500			-How HIV affects my health
		2.1600			-Self reflection of my HIV
	2.2000				ASO Workers / people and professionals
		2.2100			-People who show empathy and concern
		2.2200			-Follow through on empathy
		2,2300			-Prejudice and stigma
3.0000					HIV Treatment (ARVs)
210000	3,1000				-What helps me remember to take my meds
	211000	3 1001			Fewer nills
		3 1002			Fewer side effects
		3 1003			Trust in Nurses and Doctors
		3 1004			Physical location of ARVs (methadone)
		3 1005			Fear (understanding consequences)
		3 1006			Fewer times a day
		3 1007			Having a routine I follow everyday
		3 1008			Positive changes in CD4 and PVI
		3 1009		-	Staff at ASO's / supports / family
		3 1010			Being clean
		3 1011			Having a home
		3 1012			Increased ARV knowledge
		3 1013			Being open and honest in the community
	3 2000	5.1015			-What makes it harder for me to take my ARVs
	3.2000	3 2001			Side effects (drug interactions co-
		5.2001			morbidities)
		3 2002			Physical location of my ARVs
		3 2002			Distractions
		3 2004			Timing of when to take my ARVs
		3 2005			Being High (active addiction)
		3 2005			Homelessness
		3.2000			
		3.2007	<u> </u>		Deople (addiets)
		3.2008			The burden of taking nills everyday
	2 2000	3.2009			APV side effects
	3.3000				-AKV SIGE EJJECIS
	3.4000	2 4100			- I ne importance of treating my HIV
	2.5000	3.4100			Always on my mind
	3.5000				-How can HIV treatment work better for me

		3.5100	Communication
		3.5200	More HIV and ARV education
		3.5300	The decision to start treatment should be
			mine
		3.5400	Care providers should be more caring
		3.5500	More connection with other PLWA
		3.5600	Outreach programs
		3.5700	Incorporation of Aboriginal Tradition
4.0000			The connection between HIV and IDU
-	4.1000		-How does HIV affect my drug use
		4.1100	HIV increases my drug use
		4.1200	HIV does not increase my drug use
		4.1300	I do not share needles
		4.1400	I get sick, because my CD4 is low
	4.2000		-How does IDU affect my HIV treatment
		4.2100	IDU makes it harder to take my pills
		4.2200	IDU does not make it harder to take my pills
	4.3000		-How does IDU affect me living with HIV
		4.3100	IDU makes my forget I have HIV
		4.3200	IDU takes away the responsibility of having
			HIV
		4.3300	IDU takes away negative feelings and
			emotions
		4.3400	IDU is making me sicker (HIV worse)
5.0000			Aboriginal traditions in my life
	5.1000		-Knowledge of Aboriginal traditions
	5.2000		-Perception of self-identity (as an Aboriginal)
	5.4000		-Reconnection to traditional Aboriginal
			practices
	5.5000		-Respect and perception for/of Aboriginal
		_	traditions (my Aboriginal self)
6.0000			HIV, IDU & being Aboriginal