AN INVESTIGATION OF THE DETERMINANTS OF ADHERENCE TO HIGHLY ACTIVE ANTI-RETROVIRAL THERAPY IN ABORIGINAL MEN IN THE DOWNTOWN EASTSIDE OF VANCOUVER

by

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ABSTRACT

The eradication of HIV is not yet possible; therefore, persons undergoing treatment must take highly active anti-retroviral therapy (HAART) regularly. In British Columbia, antiretrovirals are distributed at no cost but the HIV-related annual mortality rate stands at 9 percent.

The purpose of this study was to investigate the determinants of adherence to HAART in Aboriginal men in the Downtown Eastside of Vancouver. A Vancouver School of Doing Phenomenology method was chosen for the study.

Five main determinants of adherence emerged from the data. The presence of patient factors like depression, a history of trauma/ residential school attendance, inter-personal factors like stigma and discrimination, absence of support structures, medication-related factors like a complex treatment regimen reduces adherence.

Patients may overcome some of the barriers by receiving better health education about the need for adherence, professional and lay support, and being encouraged to follow their traditional ways of living.

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GLOSSARY

Aboriginal: is defined in the Constitution of Canada and refers to all Peoples of First Nations, Inuit and Métis heritage, regardless of where they live in Canada or whether they are "registered" under the *Indian Act* of Canada.

Addiction: for the purposes of this research, addiction is defined as a process where a behaviour, that can function both to produce pleasure and to provide relief from internal discomfort, is employed in a pattern characterized by: (1) recurrent failure to control the behaviour (powerlessness) and (2) continuation of the behaviour despite significant negative consequences (unmanageability). Addiction involves both dependence (gratification of needs) and compulsion (evasion or avoidance of internal discomfort) together (Goodman, 1990).

AIDS: stands for Acquired Immunodeficiency Syndrome. A person who has AIDS has illnesses occurring after HIV infection that sufficiently compromise a person's immune system or cancers that are rare in healthy people. These illnesses, called opportunistic infections, happen when HIV has severely damaged the body's Helper T-cells of the immune system. AIDS is usually diagnosed when you are HIV positive and have one or more opportunistic infection(s).

CD4 count: a measure of the number of Helper T cells per cubic millimetre of blood, used to analyze the prognosis of patients infected with HIV. CD4 or T-cells are specialized cells in the immune system that help protect the body from infection. HIV attacks these types of cells and uses them to make more copies of HIV. In doing so, HIV weakens the immune system, making it unable to protect the body from illness and infection.

HAART: stands for Highly Active Antiretroviral Therapy. HAART was introduced in 1995 as the standard for treatment of HIV infection. HAART reduces the levels of the virus in the body, and improves HIV-related morbidity and mortality. HAART was defined by the U.S. National Institute of Heath Guidelines (USCDC, 1998) as two or more nucleoside reverse transcriptase inhibitors (NRTIs) with either a protease inhibitor or a non-NRTI, either singly or as combination tablets. In this study, respondents used ARV (anti-retroviral) to refer to HAART.

Historical trauma: a cluster of traumatic events that operate as a causal factor in a variety of maladaptive social and behavioural patterns. Hidden collective memories of trauma, or a collective non-remembering, are passed from generation to generation, just as maladaptive social and behavioural patterns are symptoms of many social disorders; or, it is a cumulative emotional and psychological wounding across generations resulting from massive tragedies.

HIV: stands for Human Immunodeficiency Virus. HIV is the virus that causes AIDS. Having HIV is also called being "HIV-positive". HIV is a retrovirus that infects humans when it comes in contact with tissues such as those that line the vagina, anal area, mouth, eyes, or a break in the skin. HIV spreads through your body and attacks your immune system, making it hard to fight off illnesses. There is no known cure.

HIV/AIDS: HIV leads to AIDS. The two are often referred to in conjunction.

IDU: injection drug use or intravenous drug use and may also refer to a user who injects drugs (typically illicit) directly into his or her bloodstream using a needle and syringe.

Legacy of residential schools – is the ongoing direct and indirect effects/ consequences (i.e., physical, emotional, cultural, and social) of psychological, emotional, physical and sexual abuse as a result of the government's policy of assimilation through residential schools. It includes the effects on survivors, their families, descendants, and communities. These effects may include, drug and alcohol abuse, physical and sexual abuse, loss of self-esteem and self-destructive behaviour.

Residential schools: the Indian Residential School system in Canada that Aboriginal students were forced into and may include industrial schools, boarding schools, homes for students, hostels, billets, residential schools, or a combination of any of the above.

Survivor: an Aboriginal person who attended and survived the residential school system which is extended to other family members, and not limited to the physical being.

Virologic failure: the inability of anti-HIV treatment to reduce viral load or to maintain suppression of viral load. Virologic failure is the most common type of treatment failure and may lead to immunologic and clinical failure.

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CHAPTER ONE

Introduction

The background of this study and adherence to the treatment of HIV/AIDS (Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome), highly active antiretroviral therapy (HAART), is conceptualised and presented in this chapter. The epidemiology of the illness is then outlined followed by a brief presentation on the factors that generally determine adherence to HAART. Thereafter the statement of the problem or rationale for the study will be given, followed by the research aim, objectives and significance. Finally, the layout of the thesis is outlined.

Background to the Study

HIV/AIDS is one of the most devastating infectious diseases since the 1917-1918 influenza epidemic that killed at least 50 million people (arguably as high as 100 million) around the world in approximately six months (Johnson & Mueller, 2002). An estimated one third of the world's population (or \approx 500 million persons at that time) was infected with influenza and had clinically apparent illness (Burnet & Clark, 1942; Frost, 1920). Significantly, in both Canada and around the world, HIV/AIDS has settled resolutely in the most vulnerable of communities (New York Times, 2001). HIV infection is indeed a serious and ongoing health concern in Aboriginal communities. Over the past few years, several reports have documented links between historic trauma/ residential schools and HIV/AIDS (Barlow, 2009; Jackson & Reimer, 2008). In fact, Aboriginal persons living with HIV/AIDS continue to be overrepresented in the HIV epidemic in Canada. There are roughly one million Aboriginal peoples living in Canada, accounting for approximately 3.8 percent of the total population (Statistics Canada, 2008). However, the Public Health Agency of Canada (PHAC) estimates that [Aboriginal peoples] accounted for 7.5 percent of persons living with HIV in

Canada at the end of 2005 and 9 percent of all new HIV infections in 2005. This shows an overall infection rate in Aboriginal persons that is nearly 3 times higher than among non-Aboriginals (Public Health Agency of Canada [PHAC], 2006).

Internationally, Indigenous peoples are also struggling with this epidemic. In New Zealand, 1,212 people have been diagnosed with HIV since 1996, 5.7 percent of the men diagnosed identify as Māori men and 0.7 percent identify as Māori women. In Australia, the rate of HIV diagnosis increased among indigenous peoples from 3.7 per 100,000 to 5.2 per 100,000 from 2000 to 2004 (United Nations Economic and Social Council [UNESCO], 2006). Much like Canada, the Kuna peoples of Panama have HIV prevalence higher than the national average (World Health Organization [WHO], 2005).

Since the eradication of HIV is not yet possible¹, persons undergoing treatment for HIV disease must take their Highly Active Antiretroviral Therapy (HAART) regularly (Ickovics & Meade, 2002a). Adherence is a primary predictor of treatment success (Bangsberg, 2006) and studies have demonstrated that taking 95 percent or more of doses is required for full viral suppression (Department of Health and Human Services [DHHS], 2009). However, HAART is a long-term treatment, and not without side effects. Therefore maintaining a high level of drug adherence often represents a big challenge for both the patient and healthcare provider (Paterson, et al., 2000). It is more so a challenge for Aboriginal peoples since many still have unresolved pain related to historic trauma and/or the residential schools legacy. A

¹ There is some hope for the future in a homozygous CCR5 delta32 deletion, observed in approximately 1% of the white population, which offers a natural resistance to HIV acquisition. Recently, a bone marrow transplant using stem cells from a CCR5-negative donor was used to treat an HIV-infected individual with acute myeloid leukemia (AML) (Hütter et al., 2009). The AML has not recurred in nearly 3 years and, most importantly, the dominant R5 virus has not been detected in the blood stream. Although not a cure, this finding encourages the use of other approaches to control HIV replication, namely by reducing CCR5 expression (Levy, 2009). The manipulation of stem cells by gene therapy to lack CCR5 and the use of vectors carrying anti-CCR5 activities are directions being tested (Cohen, 2007).

lack of self-esteem, mistrust in medical institutions, engagement in negative/ destructive coping patterns such as substance abuse, and lack of culturally safe and supportive care that stems from the residential school legacy may negatively impact the uptake of treatment for Aboriginal patients. Evidence suggests that not only do HIV-positive Aboriginal persons have sub-optimal access to HAART (Vancouver HIV/AIDS Care Co-ordinating Committee, 2000), they also have shorter survival rates than non-Aboriginal persons (Lima et al., 2006). A high proportion of AIDS mortality is therefore due to poor adherence to therapy among the disadvantaged or marginalized.

A variety of other factors have been found to predict antiretroviral adherence. Different studies demonstrate that adherence to HAART is complex, and can be potentially influenced by interaction between patient factors, drug factors and the attributes of HIV care received (Barlow, 2009; Fong et al., 2003). As such it is conceivable that antiretroviral adherence may thus differ significantly among different populations. Nevertheless, adherence to HAART should be seen as crucial to ensure viral suppression, decrease the risk of disease progression and drug resistance. Adherence to HAART is also an individual patient behaviour that is difficult to objectively measure, monitor, and improve (Simpson, 2006). Given these methodological difficulties, it is not surprising that a bewildering number of factors have been reported to influence adherence which include monthly income, travel time from home to clinic, baseline CD4 cell count, CDC HIV clinical stage before starting HAART, type of HAART regimen, presence of early HAART side-effects and disclosure of HIV status to at least one relative (Miller & Hays, 2000). Other factors and behaviours that may determine adherence to HAART include gender, self-reported race, level of education completed, sociodemographic variables (age, employment, income), lifestyle behavioural characteristics (smoking, alcohol use, recreational drug use), health care use (medical insurance coverage,

outpatient medical care), psychological factors (depression, cognitive decline), type of combination therapeutic regimen, and length of time that the patient had been taking the specific therapy (Kleeberger, et al., 2001). HIV/AIDS stigma and discrimination make it even more difficult to face and respond appropriately (Barlow, 2009).

Identification of such factors, and how they interact, may serve as reference for enhancing adherence in patients who have suboptimal adherence to HAART. This study therefore sought to identify the factors that influence adherence to HAART in Aboriginal men in the Downtown Eastside (DTES) of Vancouver. The focus was on men because, in 2006 in British Columbia (BC), the greatest number of new HIV positive infections was reported among men (CDC, 2006). In addition, with regards to high risk behaviour that may lead to HIV infection in the first place, the proportion of males reporting two or more partners is almost double that of females, with only half of the men actually using a condom in their last sexual encounter (Hansen, Mann, McMahon, Wong, 2004; Mehrabadi et al., 2008). Furthermore, males are less likely than females to access HAART (Tu et al., 2008). If the voices of Aboriginal men can be heard through this research, culturally sensitive conditions that promote adherence can be maximized prior to and after initiation of HAART.

Statement of the Problem

The impact of Aboriginal status on HIV incidence, HIV disease progression, and access to treatment has been investigated (Lima et al., 2006). There is disparity for Aboriginal persons when considering access to treatment for HIV. In BC, Canada, where anti-retrovirals are distributed at no cost (BC-CfE, 2010), Aboriginal ethnicity has been shown to be negatively associated with receiving HIV treatment before death (Lima et al., 2006; Wood et al, 2003b). However, little is known about the determinants of adherence to HAART in the DTES Aboriginal community and about the impact of historic trauma on HAART outcomes.

Research has shown that there is a significantly higher mortality risk for Aboriginal persons after the initiation of HAART (Lima et al., 2006). After adjustment for confounder variables (socioeconomic status and behavioural factors), the mortality rate for Aboriginal persons was shown to be more than three times higher than that of non-Aboriginal persons. The main clinical characteristic (as opposed to others such as hepatitis) associated with mortality risk in this population was adherence during first year of follow-up. Poor adherence was the strongest predictor of adverse outcomes in all analyses (Lima et al., 2006). My research sought to identify factors associated with poor adherence and to find out how much historic trauma/residential schools legacy contributed to low adherence to HAART, and subsequently to the higher rate of mortality in HIV – positive Aboriginal men. The focus was on men because research has shown that men are less likely than women to access HAART (Tu et al., 2008). Few non-Aboriginal homes can claim the same level of HIV-related premature deaths that occur in many Aboriginal communities (Barlow, 2009).

Cohort and population based studies have confirmed the impact of HAART in terms of reductions in AIDS-related death rates, opportunistic infections, and hospitalization (Hogg et al., 1999; Murphy et al., 2001). Despite these advances, the full benefit of antiretroviral regimens remains difficult to achieve in clinical practice due in part to imperfect adherence. Incomplete adherence to antiretroviral treatment has been shown to be an important cause of virologic failure (Descamps et al., 2000). Patients taking antiretroviral drugs intermittently or at reduced doses often experience suboptimal drug levels thus increasing the likelihood of drug resistance (Miller et al., 2003). Moreover, resistance to one drug is frequently associated with cross-resistance to other members of the same class (Kozal, 2004) thus limiting future treatment options. This problem is compounded by the possibility that multidrug resistant

viruses can be transmitted from HIV-positive persons on HAART to sexual and injecting drug user networks (Hogg et al., 2002).

According to Tu et al. (2008), the Aboriginal population in BC alone makes up 13% of new HIV infections, many of whom are less likely to engage in effective care. The Vancouver Native Health Society (VNHS), established in 1991, delivers medical, counselling and social services, with an emphasis on providing care to the Aboriginal community. All programs are accessible without fees to individuals residing in Vancouver's DTES. A recent VNHS report showed that the number of HIV-positive Aboriginal patients served has increased from 327 (52%) in 2006-2007 to 349 (57.6%) in 2008-2009 (VNHS, 2008/2009). Around 33% of these patients are on HAART but females with a CD4 <250 are more likely than males to access treatment (p = 0.046) (Tu et al. 2008). There is no explanation in this report as to why males access HAART less frequently than females. However, this may be because there has been fundamental progress in dealing with issues of violence and safety in reaching out to women for HIV/AIDS care, support and treatment (VNHS, 2008). The HIVrelated annual mortality rate stands at 9%. In 2008, 57 clients passed away, 26 of which were Aboriginal and 31 non-Aboriginal (VNHS, 2008/2009). There is therefore a grave problem of sub-optimal adherence to HAART locally. To compound this problem, according to the Health Sciences Association (HSA, 2009), the BC Health Ministry recently marked World AIDS Day by delivering severe funding cuts to community-based health organizations (CBHO's) that provide services to HIV/AIDS patients. Given that 18% of Canada's estimated total HIV-positive population lives in BC, and that the province represents approximately 13% of the overall population of Canada, BC will continue to have a disproportionate share of the HIV burden.

According to a recent BC Centre for Excellence (BC-CfE) in HIV/AIDS 2010 report, British Columbia launched a four year, \$48-million pilot project, called Seek and Treat, to find and treat hard-to-reach, underserved populations including Aboriginals peoples, drug users, men who have sex with men and sex workers who are undiagnosed or untreated for HIV in Vancouver's DTES (BC-CfE, 2010). More than 12,000 people in B.C. are living with HIV, with 27% undiagnosed (BC-CfE, 2010). The plan of Seek and Treat is to reach and engage more people living with HIV/AIDS in HAART, provide better care and treatment, and significantly reduce or eliminate the ability of the virus to spread. Better care and treatment will also result in decreased progression to AIDS among HIV-infected individuals and fewer new HIV infections among those at risk. Mathematical modelling suggests the pilot project could avert as many as 173 HIV infections in the first five years, representing an estimated \$65 million in avoided lifetime HIV treatment costs (BC-CfE, 2010). Granted, HAART's potential to prevent new HIV infections is an important element of the overall strategy to minimize the economic burden on the health care system of treating HIV and the project is a good effort of outreach and support; however, I would argue that improving adherence to HAART in patients who are already on treatment could greatly supplement this effort and therefore funding for specific organizations (such as the VNHS) that deliver HAART should not have been cut in the first place.

While poor adherence and high mortality rates give one an idea of how many lives have been touched by the historic trauma/ residential school legacy, they cannot begin to capture the physical, psychological, spiritual and cultural harm inflicted on survivors, their families and communities (Dion-Stout & Kipling, 2003). Indeed, intergenerational trauma, defined by indigenous scholars as the transmission of a collective emotional and psychological injury over the lifespan and across generations among Aboriginal people, continues to affect the health and well-being of young Aboriginal peoples (Mehrabadi et al., 2008; Yellow Horse & Brave Heart, 2004). The forced assimilation of residential school, for example, meant loss of language, identity, culture, Aboriginal ways and values, family, and loss of identity (Burtinshaw, 2007). One of the hardest losses to deal with, for many, was the loss of self-esteem. For residential school students, being told that they were no good, and being forced to change to fit into the world, meant a childhood governed by shame and fear (Cyr, 2009).

Because of the links involved, the solution to truly overcoming the impact of residential schools may help in overcoming HIV/AIDS; the solution may be to be informed and not to be afraid to speak out, to be motivated to take control of one's destiny, to confront the trauma, multigenerational abuse, and colonial policies, and to foster a willingness to change or try a new behaviour. Through knowledge and reason, Aboriginal peoples can rely on their traditional strengths to face any challenge that comes their way (Barlow, 2009). Understanding the mechanism by which such health care disparities exist by determining what other aspects of being Aboriginal increase their risk of mortality after initiating HAART can provide potential targets for intervention in this vulnerable population. Results could be further extrapolated to the understanding of health care inequalities amongst other marginalized populations (Lima et al., 2006). Early detection of non-adherence and prompt intervention can greatly reduce the development of viral resistance and the likelihood of virologic failure (Department of Health and Human Services, 2009). Today Aboriginal peoples in general, and some survivors of Canada's residential schools, are no longer silent – instead they are on a path to healing, but before the healing begins, some have suggested that they must speak out about the loss of language, identity, culture, Aboriginal ways and values and the loss of family (Burtinshaw, 2007) and how their unresolved pain affects adherence to HAART.

For hundreds of years, Canadian Aboriginal communities experienced wave after wave of debilitating shocks and traumas that left whole nations of people reeling and broken. These shock waves came in many forms: diseases, the destruction of traditional economies through the expropriation of traditional lands and resources, the undermining of traditional identity, spirituality, language and culture under the auspices of a mission, and through residential schools, the destruction of indigenous forms of governance, community organization, solidarity, and cohesion through the imposition of European governmental forms, and the breakdown of healthy patterns of individual, family and community life and the gradual introduction of alcohol and drug abuse, family violence, physical and sexual abuse, the loss of the ability to have or maintain intimate relationships, the loss of the ability to love and care for children, chronic depression, anger and rage and greatly increased levels of interpersonal violence and suicide (Lane et al., 2002).

When considering these various sources of trauma, the eventual impact of trauma originating from outside Aboriginal communities was to generate a wide range of dysfunctional and hurtful behaviours (such as physical and sexual abuse) which then began to be recycled, generation after generation inside communities. As many as three to five generations removed from externally induced trauma, the great great grandchildren of those who were originally traumatized by past historical events are now being traumatized by patterns that continue to be recycled in the families and communities of today (Lane et al., 2002). The result of this trauma is a wide range of personal and social dysfunction that translates into many different symptoms that include, for example, individuals who can neither trust, persevere when difficulties arise, nor leave behind harmful habits such as alcohol and drug abuse. When individuals who are stuck enter family life, the family becomes a generator of trauma and dysfunction, as patterns of addictions and abuse are

passed on. Basic human needs for safety, security, love and protection are not met and the family system is no longer able to provide the foundation for healthy community life, as it once did in traditional society. However, it is worth noting that whether historic trauma/ residential school legacy is a determinant of adherence has however been assumed, rather than investigated.

Research Aim

To investigate the determinants of adherence to highly active anti-retroviral therapy (HAART) in Aboriginal men in the Downtown Eastside (DTES) of Vancouver and to offer culturally-sensitive recommendations to better address the effects of the determinants and/ or unresolved pain, aimed at improving access to HAART among Aboriginal men and reducing deaths due to HIV/AIDS.

Research Objectives

(1) To investigate the determinants of adherence to HAART in Aboriginal men in the DTES of Vancouver.

(2) To assess whether the effects of historic trauma/residential schools impact HAART outcomes in Aboriginal men in the DTES of Vancouver.

(3) To assess the effects of selected determinants, and offer recommendations to improve adherence to HAART in Aboriginal men in the DTES of Vancouver.

(4) To offer culturally-sensitive recommendations (learned from participants) to better address the effects of the determinants and/ or unresolved pain, aimed at improving access to HAART among Aboriginal men and reducing deaths due to HIV/AIDS.

Significance of the Study

The study is important not only to the Aboriginal community of the DTES but to Canada as a country. The study will help me, healthcare providers and others get a better insight/

understanding and depth into the determinants of adherence to HAART in this community which may be used to inform policy.

Most Aboriginal men suffer cumulative trauma and have troubled personal histories that may affect their ability to manage adverse situations such as HIV/AIDS. The associated stigma, low self-esteem, and perceived inability to heal may affect adherence to, and hence outcomes of, treatment. More and more Aboriginal men continue to die prematurely of HIV/AIDS despite the availability of free antiretroviral therapy. Knowledge gained from participant's experiences may contribute to the body of knowledge related to HIV/AIDS, its management, and the complexities of relationships for this population.

An important consideration for researching this topic is my lived experience. My interest in HIV/AIDS, and the field of medicine itself, began twenty years ago when my own relatives suffered and succumbed to HIV/AIDS in the midst of very little understanding of the disease and the belief that it was a taboo to even speak about it. I am now a medical doctor who has worked extensively with those affected by HIV/AIDS and disadvantaged communities in Africa. I believe this experience prepared me to be able to investigate this population and gave me the passion for understanding the plight of those living with HIV/AIDS. It was, and still is, my view that in order to tackle low adherence to HAART, a solely biomedical position is insufficient as it does not account for social and historic aspects of life in Aboriginal peoples. It may be necessary to engage with a multidimensional health conceptual framework in order to provide a more efficient way of understanding not only the illness aspect of HIV/AIDS but also the treatment of patients in that it may recognize psychological and social settings that both the affected and effected encounter. A thorough study of this topic therefore had to include a critical evaluation that extended beyond understanding phenomena but considered active participation and holistic approaches in order to bring about improvements to adherence to HAART.

Another consideration was that, the situation in Africa, where I grew up, is unique in that there is a constant lack of medication. However, here in Canada, specifically BC, HAART is available and free. To then find that those affected most by HIV/AIDS have low adherence to HAART, a history of trauma, and are still marginalized today signalled the importance of undertaking this study. I believe that there is a collective and universal responsibility that we all share in fighting HIV/AIDS that can start with the understanding of one's history, personal circumstances, and how they go through everyday life through opening up to such sensitive but personal stories as was done in this study. In line with Guba and Lincoln (1981), knowledge is taken as only understood within the social context in which it takes place. The meaning therefore of a particular utterance or interaction can only be understood and has meaning only within the specific context in which it occurred (Hathaway, 1995; McCracken, 1988). This understanding required a complex appreciation, on my part, of the overall context in which the phenomenon occurred. I took context here as referring to the complete fabric of local culture, people, resources, purposes, earlier events, and future expectations of the immediate and particular situation (Guba & Lincoln, 1981) of the dynamics of adherence to HAART.

Finally, because of my lived experience, I decided I would set aside preconceptions of my meagre grasp of the world of adherence and HIV/AIDS in order to allow the meaning of the phenomenon to emerge from the Aboriginal men in this study. The study therefore reflects what is true to the lived experience of the participants.

Outline of the Thesis

Chapter 2 is the literature review which brings out the importance of understanding the residential school legacy, and includes a review of Aboriginal people and HIV/AIDS, the drug treatment program, access to and discontinuation of HIV treatment, and the factors that influence adherence to HIV treatment. The methods and methodology section (Chapter 3) explains the research paradigm of phenomenology and highlights The Vancouver School of Doing Phenomenology. The results of the study are brought out in Chapter 4 illustrating the essence of the phenomena. The last chapter (Chapter 5) includes a discussion of the determinants of adherence to HAART, and highlights key implications for practice and puts forward prospects for future research.

CHAPTER TWO

Literature Review

Introduction

This chapter is organised into five sections. First, salient literature relating to the residential school legacy and its effects is presented to help the reader understand the harsh colonial practices that Aboriginal people were put through and the historic trauma they continue to suffer today. It also helps to understand the second section which presents indices relating to HIV/AIDS in relation to Aboriginal people. The drug treatment program, as well as access to and discontinuation of HIV treatment, is then reviewed with a specific focus on Aboriginal men in order to provide an understanding of the management of the illness in the same population. Finally, literature on factors that influence adherence to HIV treatment in the general population are then presented under issues relating to medication factors, patient factors, patient-provider relationship and clinic setting, disease characteristics, and other factors such as stigma and discrimination, and social support. Understanding these factors will serve as a point of comparison and help illuminate determinants that may be different or that may stand out from the population in this study.

Understanding the Residential School Legacy and Its Effects

Aboriginal peoples in Canada have faced cultural oppression through policies of forced assimilation on the part of Euro-Canadian institutions since the earliest periods of contact (Barlow, 2009). Particularly notable was the establishment of the residential school system, a result of Federal Government policy and culmination of a formal partnership between the Government and the churches (Catholic, Anglican, Presbyterian, Methodist and United) to educate Aboriginal children (Barlow, 2009). Church-operated residential schools in Canada closed in the late 1960s: "Residential schools officially operated in Canada between 1892 and

1969" (Aboriginal Healing Foundation [AFN], 2001, p. 7), but government-run schools continued until 1996 with the last band-run school closing in 1998 (Barlow, 2009). From 1831 to 1996, there were 150 residential schools in operation in Canada whose goal was "to kill the Indian in the child" (AFN, 2010). The purpose of residential schools was to strip Aboriginal children of their culture by stripping Aboriginal cultures of their children (Wade, 1995) explicitly in order to promote the assimilation of Aboriginal peoples to a society modelled on European cultural traditions. Wherever possible, the authorities established residential schools rather than day schools so that the education of the children could be done without daily "contamination" from Aboriginal parents, family and community (Wade, 1995).

In contrast to traditional Aboriginal ways of learning and parenting, children in residential schools were taught, or rather disciplined, to be ashamed of their culture, history, languages, and ways of life (Hylton, 2002; Milloy, 1999). Furthermore, children in residential schools were subjected to many forms of abuse, sexual abuse being the most pervasive and disastrous (Walters & Simoni, 2002). Residential schools also utilized strict discipline, regimented behaviour, submission to authority, and corporal punishment (Furniss, 1995; Pearce et al., 2008). Following a residential school experience, students often brought back to their communities what they had learned about control and abuse, and inflicted it upon their own children (Pearce et al., 2008). For many years, it was taboo to speak about the terrible impact of the schools on the students and on the families of the students who were forced to attend them.

Criticism and resistance from Aboriginal communities, much of it articulated by former students, was a major factor in the movement away from residential schooling for Aboriginal children after the Second World War. Opposition to the sort of education that had been

provided for them surfaced in a major parliamentary inquiry into the Indian Act in the latter half of the 1940s, and later in a series of policy reviews in the 1950s and 1960s. The objections that Aboriginal leaders expressed on these occasions added to the widespread doubt in Canadian society at large about Indian affairs policy. The opposition of Aboriginal political leaders and the equivocal support of some of the Christian denominations dovetailed with the increasing unease of the federal government about the viability of its schools' policies in a time of dramatic change (Miller, 1996). However, the minister responsible for Indian Affairs acknowledged in 1944 that the whole Act needed a thorough revision, and representations from Aboriginal groups also supported the idea of a thorough overhaul of the legislation (Leslie & McGuire, 1978) leading to the creation of a Special Joint Committee in 1946. There were numerous and forceful criticisms that the committee heard directed at residential schools. In marked contrast to Indian Affairs and church views, almost all Aboriginal representatives rejected the underlying assimilationist aim of residential schools. Some of the adverse determinants to adherence to HAART in Aboriginal people, being attributed to the effects of historic trauma, are therefore not embraced as having come from within Aboriginal communities and should be treated as such.

The impact of the residential schools in Canada on Aboriginal people should not be underestimated. Generations of Aboriginal people were and continue to be negatively affected by their experiences in residential schools. Through education, it was thought that Aboriginal children could be integrated into the emerging British Canadian society and imbued with the principles and knowledge required to progress toward civilization (Kirmayer, Simpson, & Cargo, 2003). However, many Aboriginal people did not possess the power or means to resist government policy (Barlow, 2009) resulting in cultural strengths, such as the extended family-based system, decreasing in their effectiveness to address the imminent threats, such as physical and sexual abuse, commonly found within residential schools. Survivors experienced trauma during their educational training, and these traumas have been multi-generational, spilling over to their descendants. Some resultant attitudes and behaviours secondary to residential schools' disciplinary regimes, corporal punishments and estrangement from families, have led to many survivors suffering consequences, especially in how they perceive themselves (Dion-Stout & Kipling, 2003). There was damage to the individual, which resulted in shame, lack of trust, and engagement in negative coping patterns such as substance abuse, among others. These attributes, coupled with marginalization and isolation, may increase the risk of HIV infection for some survivors (Barlow, 2009).

Policies of forced assimilation are prime causes of poor health and social outcomes in Aboriginal peoples (Kirmayer, Simpson, & Cargo, 2003). The literature pertaining to the effects of residential schools on the health of Aboriginal peoples in Canada is, at best, limited. However, Aboriginal peoples have limited access to or use of health care services, both of which increase their vulnerability to HIV infection (Barlow, 2009; Health Canada, 2004). For example, in 2006/2007, the age-standardized utilization rate for the Medical Services Plan (MSP) was 16 per cent lower for the First Nations population compared to other residents (708.1 per 1,000 compared to 844.0 per 1,000) in BC. (British Columbia Provincial Health Officer, 2009). In the same vein, residential schools have been a contributing factor in why some survivors have contracted HIV/AIDS. This observation also applies to later generations. It is more likely that those individuals with severe unresolved trauma may be at greater risk for HIV/AIDS based on whether certain high-risk behaviours are present (Barlow, 2009).

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Despite scarcity of empirical evidence of the relation between sexual abuse, for instance, and HIV infection among Aboriginal people, a large body of literature strongly links HIV susceptibility among vulnerable populations to previous sexual trauma (Braitstein et al., 2003; Whetton et al., 2006). Of note here is that, it is widely accepted that sexual abuse in Aboriginal communities was relatively rare prior to colonization, and traditional child protection mechanisms effectively enforced moral codes (Aboriginal Peoples Collection, 1997; Fournier & Crey, 1997). Following European colonization, however, Aboriginal cultural principles that promoted a sacredness of sexuality were demolished, reducing the impact of preventative values and traditions (Chester et al., 1994; Mehrabadi et al., 2008).

Additionally, the weight of historical events of the residential school system leads to negative and destructive coping mechanisms, such as substance abuse (Barlow 2003; Craib et al., 2003; Ship & Norton, 2001), can increase the risks for, as well as reduce survival from, HIV (Barlow, 2009). Vulnerability to drug-related HIV risk is greater among the sexually abused and the same group are more likely to have either overdosed or injected drugs before (Pearce et al., 2008). A lack of trust in government and health organizations means that many do not use them for diagnosis and treatment (Brown & Fiske, 2005; Vernon, 2001; Williams & Guilmette, 2001). This mistrust is built on many historical elements ranging through colonialism, assimilation policies, and residential schools (Barlow, 2003; Brown & Fiske, 2005; Marsden, et al., 2000). This means that support systems are not always considered "friendly" (Rowell in Mann & Tarantola, 1996, p. 438). Racism and cultural insensitivity in today's mainstream health services continue to compound this distrust (Brown & Fiske, 2005). Hence, persons living with HIV/AIDS commonly advocate for increased Aboriginal representation at the front-line of HIV/AIDS services.

Residential schools were founded on the model of the "total institution". A conscious effort was made to strip children of any meaningful links to their families and cultures and to assimilate them to the status of second class citizen (Wade, 1995). Rigid church doctrine combined with many forms of punishment led to conflicts and trauma for survivors, many of which often remained unresolved. Christian teachings toward sex and sexuality, in general, were strict and unbending. Aboriginal students were pressured to maintain abstinence until marriage. It was confusing for many of the students to be taught that sex is for procreation upon marriage by the same people who committed violent sexual acts against them (Barlow, 2009). Psychological and emotional abuses were constant: shaming by public beatings of naked children, vilification of native culture, constant racism, public strip and genital searches, withholding presents and letters from family, locking children in closets and cages, segregation of sexes, separation of brothers and sisters, prohibition of native languages and spirituality (AHF, 2002). In addition, the schools were places of profound physical and sexual violence; sexual assaults, forced abortions of staff-impregnated girls, needles inserted into tongues for speaking a native language, burning, scalding, beating until unconscious and/or inflicting permanent injury (Truth Commission into Genocide in Canada, 2001). Students also endured electrical shock, force-feeding of their own vomit when sick, exposure to freezing outside temperatures, withholding of medical attention, shaved heads (a cultural and social violation), forced labour in unsafe work situations, intentional contamination with diseased blankets, insufficient food for basic nutrition and/or spoiled food, and the strict monitoring and regulation of diet and access to food (Wade, 1995). To maintain what school authorities considered discipline and order, children were subjected to a continuous and virtually complete surveillance, authorities expected instant obedience, affection was contingent on submission, food was withheld (almost to starvation) as punishment, and

militaristic standards of neatness and tidiness were enforced (Wade, 1995). Research suggests that many of the students died (due to illness, beatings, attempts to escape, or suicide) while in the schools (Indian Residential School Survivors Society, 1994; Milloy, 1999). Furthermore, Aboriginal children were forced to live away from their parents for the duration of the school year and not allowed to speak their native languages, engage in any activities that were remotely connected to their cultures, or have any type of relationship with their tribal roots (Duran & Duran, 1995). This unresolved trauma could have led to feelings such as intense shame, low self-esteem and powerlessness that may interfere with the completion of important life prolonging tasks for HIV patients such as adherence to taking medication. A "history of hopelessness" and shame may keep people from being tested in the first place, and for some patients already living with HIV/AIDS, they may feel hopeless to a point where they no longer care about their health (Vernon, 2001).

A number of societal norms and myths arising from long decades of forced assimilation and genocidal practices implemented by the federal government complicate the situation. They include the belief that one cannot trust Aboriginal people and that this group of people are disposable (Cyr, 2009). Once a group of people have been assaulted in a genocidal fashion, there are psychological ramifications. With the victim's complete loss of power develops despair, and the psyche reacts by internalizing what appears to be genuine power – the power of the oppressor (Duran & Duran, 1995). This internalized oppression is manifested as frustration, and powerlessness, finding fault in oneself, criticizing or invalidating oneself, having a diminished will to live, fear, mistrust, accepting a narrow and limiting view of one's value to society.

Apart from being subjected to the residential school system, Aboriginal children also went through the era of the child welfare system (Pearce et al, 2008). Citing Aboriginal families as

having little or no access to basic housing and childcare (Fournier & Crey, 1997), the federal government, from the year 1951, began to delegate authority over the educational, health, and welfare services of Aboriginal people from the Indian Act (1876) to each province. With this authority, and on the background of perceived poverty and neglect within Aboriginal families as a rationale, for each Indian child they apprehended, provincial social workers were guaranteed payment. As a result of this apprehension drive, Aboriginal children comprised only four percent of the national population but more than thirty percent of all legal wards (Fournier & Crey, 1997) by the late 1960s. Today, Aboriginal children continue to be overrepresented within the foster care system (Mehrabadi et al, 2008). This fact of being forcibly taken away from one's own family at such a tender age, coupled with abuse occurring in some foster homes, may also have been a cause of trauma in these children.

Most literature is about one's experience of the effects of oppression and is devoid of one's engagement in a resistance to oppression as an Aboriginal person. Specifically, there has been little recognition of the spontaneous resistance of Aboriginal persons to the various forms of oppression they have experienced. To make the situation worse, European imperialism used strategies to conceal and suppress the resistance of its victims and sometimes typically portrayed resistance as resulting from deficiencies inherent in the Aboriginal (Wade, 1995).

Stories that recount only violence and trauma, though important to tell, often lead to the mistaken conclusion that the violence went unopposed, and was "successful" in a total or complete sense (Wade, 1995). Stories of violence and oppression which include a detailed account of resistance may have quite a different effect. They can be both political and therapeutic stories in the sense that they have the capacity to inspire and incite anyone to engage in an even more active resistance to any oppression that he/she might be

experiencing. The resistance is reflected in some survivors as they talk of their hardened strength to fight and carry on living and they attribute it as coming out of residential school. It is only through healing of individuals and community that the legacy and cycle of abuse can be broken (Cyr, 2009b).

Aboriginal communities, in the face of historic trauma/ the residential school legacy, have long argued for healing (e.g., Four Worlds, 1986). Within the last few years, there has been a significant move towards the notion that individual and family healing are mostly responses to historical forces of structural oppression and colonialism (such as residential schools). As such, they are located within a wider context of decolonization, community renewal and the reshaping of an identity and place within the wider Canadian society (Bopp et al., 1988).

Through a meeting in 1982 of Aboriginal people from across North America emerged the belief and understanding that Aboriginal peoples can build and live in communities free of alcoholism and drug abuse (Four Worlds, 1996). The key guiding principles for building a sustainable world that came out of this meeting are summed up as; "Starting from within, working in a circle, in a sacred manner, we heal ourselves, our relationships and our world" (Four Worlds, 1996). Today Aboriginal peoples continue to speak out. In turn, they ask that we listen (Burtinshaw, 2007).

Aboriginal People and HIV/AIDS

According to the Public Health Agency of Canada (PHAC), "Before 1993, 1.2 percent of reported AIDS cases were among Aboriginal peoples" (PHAC, 2004, p. 2). In 1998, there were 19 per cent of positive HIV test reports among Aboriginal people. "However, in 2006 the proportion of positive HIV test reports attributed to Aboriginal persons was 27.3 percent among the provinces and territories reporting ethnicity information with their HIV reports" (PHAC, 2007, p. 49). PHAC also reports that "Of 605 Aboriginal AIDS cases reported up to

December 31, 2006, 73.1 percent or 442 were First Nations, 7.3 percent or 44 were Métis, 3.6 percent or 22 were Inuit, and 16.0 percent or 97 were in the category Aboriginal Unspecified" (PHAC, 2007, p. 55) and that HIV infections among Aboriginal people have been on a steady rise over the last decade or so. Aboriginal persons accounted for approximately 200 to 400 of the new HIV infections in 2002 and 2005, which is about 9 percent of the total for 2005 and 10 percent for 2002. Therefore, the overall infection rate among Aboriginal persons is about 2.8 times higher than among non-Aboriginal persons (Barlow, 2009; PHAC, 2007). According to Statistics Canada (2008), it has been reported from the 2006 Census that the Aboriginal population has grown due to reporting in the Métis population, to represent almost 4 per cent of Canada's total population, an increase of 45 per cent since 1996. The Aboriginal population increase is also attributed to the introduction of Bill C-31 in 1985. This bill led to an expansion of the population entitled to Indian registration by allowing for the re-instatement of Registered Indian status to individuals who lost their status under the old Indian Act, mostly women who married non-Registered Indian men, and the "first time" registration of their children, as well as registration of children born to a Registered Indian on or after April 17, 1985 (Clatworthy, 2001). Based on the fact that Aboriginal people represent only a small percentage to that of the national population as a whole, despite its growth, this does show an overrepresentation in the higher percentage rates of HIV and AIDS infections among Aboriginal peoples. Clearly, these figures are disturbing even though they may in part be linked to better screening and reduced stigmatization.

There are approximately 55 to 70 new positive HIV tests (or new diagnoses of HIV) among Aboriginal peoples in BC per year. While Aboriginal peoples represent approximately 5 percent of the BC population, they account for 15 to 17 percent of all new positive HIV tests each year (BC Provincial Health Officer, 2009). Aboriginal females make up 30 to 40

percent of the cases among the total female population, while Aboriginal males make up 10 percent of the cases among the male population (BC Provincial Health Officer, 2009).

An added concern is that, a significant proportion of Aboriginal people are becoming HIV-infected at younger ages than in the mainstream population and that unprotected sex continues to occur among youth. Aboriginal youth are approximately three times at greater risk than non-Aboriginal youth to get infected. Aboriginal persons with a diagnosis of HIV tend to be younger than non-Aboriginal persons. 32.4 percent of the positive HIV test reports from Aboriginal persons from 1998 to the end of 2006 were younger than 30 years as compared with 21.0 percent of this age among infected non-Aboriginal persons (Barlow, 2009; PHAC, 2007).

The rate of deaths due to HIV disease for the Status Indian population has more than doubled since 1993 (0.8 per 10,000 in 1993 to 1.9 per 10,000 in 2006), while the rate for other residents has decreased significantly in the same time period (0.8 per 10,000 in 1993 to 0.2 per 10,000 in 2006). Furthermore, aggregate regional data for 2002–2006 show that the Status Indian rates of death due to HIV disease were significantly higher than the rates for other residents in BC as a whole, and in almost all health authorities (BC Provincial Health Officer, 2009). According to a 2009 report by Swinkels, the higher rates of HIV deaths in the Status Indian population may be attributed to disproportional representation of Aboriginal people in populations that are medically eligible for HAART but are hard-to-reach and therefore do not access treatment (Swinkels, 2009). Furthermore, the uptake of treatment for Aboriginal patients may be secondary to lack of self-esteem or trust in medical professionals and institutions that stems from the historic trauma/ residential school legacy, as well as the low availability of culturally safe and supportive care (BC Provincial Health Officer, 2009).

HIV/AIDS drug treatment program

In British Columbia, all anti-HIV medications have been centrally distributed at no cost to eligible HIV-infected individuals through the British Columbia Centre for Excellence in HIV/AIDS Drug Treatment Program since 1992 (BC-CfE, 2010). The center distributes antiretroviral medications on the basis of specific guidelines generated by a therapeutic guidelines committee (Lima et al., 2006; Wood et al, 2003b). The goal of antiretroviral therapy is to reduce and maintain a plasma HIV-1 RNA level below 50 copies/ mL, regardless of previous treatment experience or prior existence of drug resistance. This has become achievable in the vast majority of patients with virologic failure, even those with multidrug resistant HIV (Montaner, 2009). The BCCfE guidelines recommend that once an individual starts treatment, plasma viral load and CD4 cell count be monitored at baseline (time of enrolment) and tested at regular intervals (e.g., every 3–4 months) or after virologic rebound (Lima et al., 2006). The nature and frequency of this monitoring is partly dependent on the regimen but generally varies from monthly to every 3 months. The virology laboratory at St Paul's Hospital does all viral load measurements in the province of BC.

Since the first introduction of HAART at the Vancouver International AIDS Conference in 1996, antiretroviral therapy has been beneficial in the management of HIV disease (Carpenter et al., 1996). HAART stops HIV replication on a sustained basis and, as a result, plasma HIV RNA concentration (henceforth viral load) typically becomes undetectable. Recent data, for example, demonstrates a steady increase in the rate of undetectable plasma viral load among HIV positive patients on treatment in BC, reaching rates of over 80 percent consistently since 2005 (Lima et al., 2008; Montaner, 2009). A long period of an undetectable plasma viral load state allows for immune system recovery and delays the onset of AIDS (Hogg et al., 1997). In addition to decreasing plasma viral load to undetectable
levels, HAART decreases viral load in other biological fluids, including semen and vaginal secretions (Cu-Uvin et al., 2000; Vernazza et al. 1997). New antiretroviral medications in various combinations now allow individuals to live much longer. Often, once people develop HIV, they could live up to 15 to 20 years before the more serious threats become evident (Barlow, 2009; Wood et al., 2003a). Antiretroviral regimens have therefore proved to be effective in decreasing HIV plasma viral load, improving CD4 cell counts, and have substantially altered the natural history of HIV infection (Moore & Chaisson, 1999). As a result, substantial improvements in HIV-related morbidity and mortality have been documented among persons receiving appropriate antiretroviral regimens (Wood et al., 2003a).

New evidence suggests that HAART can decrease HIV transmission in other settings. Reductions in rates of HIV transmission of more than 90 percent have been reported in several cohort studies of heterosexual HIV serodiscordant heterosexual couples (i.e., relationships made up of one positive partner and one negative partner) in whom the index partner was treated with HAART (Attia et al., 2009; Donnell et al, 2010). More recently, this association has also been substantiated in a longitudinal cohort where reduction in community viral load as a result of HAART was shown to be a key determinant of decreasing HIV incidence in intravenous drug users (IDUs) in Vancouver, Canada (Wood et al., 2009). A recent study also reported a strong and significant population-level association between increasing HAART coverage and decreased number of new HIV diagnoses per year in the population of BC (Montaner et al., 2010). According to this study, in BC, the number of individuals receiving HAART increased from 837 to 5413 from 1996 to 2009. In the same period, individuals newly testing positive for HIV decreased from 702 to 338 per year. When antiretroviral use expanded because of initial roll-out of HAART (1996-99), or because more

aggressive treatment guidelines were implemented (2004-09), new HIV diagnosis decreased sharply (40 percent and 23 percent respectively) per year. Montaner and colleagues (2010) also noted that their results were mainly driven by a significant decrease per year in those with a previous history of injection drug use (IDU). This beneficial effect of HAART occurs because the widespread use of antiretroviral drugs reduces, at a population level, the average viral load, translating into an average reduction of infectivity and transmission (Cohen & Gay, 2010). The extent of this secondary effect of HAART (i.e., reduction of HIV transmission) however depends on the proportion of HIV-infected individuals treated, the ability to provide therapy to patients most likely to transmit HIV, the extent of viral-load control, the emergence of drug-resistant strains of the virus, and the effect of treatment on risk behaviours (Maggiolo & Leone, 2010). This is on the assumption that HIV transmission occurs only through HIV-infected individuals and that viral load is the most relevant risk factor for any method of transmission (Attia et al., 2009).

However, all this cannot be said with certainty for those living on-reserve given that knowledge about HIV testing and care in these Aboriginal communities is limited. Another problem is that some people may face discrimination within their home communities. Furthermore, according to Brotman and colleagues (2002), discrimination in rural communities can lead to lack of trust in the confidentiality of on-reserve health services. This often leads to an exodus of patients to cities where they experience isolation and not the anonymity they expect (Brotman et al., 2002). That being said, Health Canada's First Nations and Inuit Health Branch (FNIHB) has taken steps to curb the HIV/AIDS epidemic among Aboriginal peoples on-reserve by facilitating care and support for patients and developing the knowledge and tools to prevent HIV transmission. According to the FNIHB 2003-2004 HIV/AIDS work plan, over \$1.1 million funding was provided for development of bilingual

guidelines that are appropriate for and sensitive to the needs of Aboriginal communities and that can serve as a foundation for consistent standards nationally in the provision of HIV/AIDS care to on reserve. A youth peer education program was also set up to train trainers who will educate other youth in their respective communities thus promoting knowledge and information on HIV/AIDS (Health Canada, 2004). Furthermore, Health Canada provides funding to communities to help them prevent HIV/AIDS and develop outreach programs (Health Canada, 2004).

The currently available medication regimens are used to treat HIV disease with the aim of preventing progression to AIDS or death by suppressing plasma HIV RNA. However, it is not yet considered possible to eradicate HIV from the individual. Individuals undergoing treatment for HIV disease must therefore take a daily regimen of at least three antiretroviral drugs (i.e., highly active antiretroviral therapy, or HAART), and follow a scheduled dosing protocol (Ickovics & Meade, 2002a; Wood et al., 2003a).

Access to and discontinuation of HIV treatment

High levels of ongoing HIV/AIDS mortality persist and, in a large part, are due to limited access to HAART (Wood et al., 2000). In the developed world, there is growing evidence that a high proportion of the ongoing AIDS mortality is due to poor access to HAART among marginalized populations (Wood et al., 2003a). However, low adherence to daily therapy and inability to tolerate the side effects of HAART may be contributing to some of these deaths. Limited retention in treatment and poor access to HAART is of particular concern for Aboriginal populations, and may involve treatment discontinuation and/or intermittent use of HAART. This concern is real here in BC, and is contributing to ongoing AIDS mortality, despite HIV/AIDS patients being eligible for HAART free of charge. Since this suboptimal

adherence may result in reduced treatment response, conditions that promote adherence should be maximized prior to and after initiation of HAART (DHHS, 2009).

This is a challenge because many Aboriginal peoples still have unresolved trauma secondary to the residential schools legacy which may affect their adherence to treatment. Furthermore, there is some evidence to suggest that Aboriginal persons living with HIV in Vancouver are accessing combination drug therapies at a rate significantly lower than their non-Aboriginal counterparts (Barlow, 2009; Vancouver HIV/AIDS Care Co-ordinating Committee, 2000) and that HIV-infected Aboriginal persons accessing HAART have a shorter survival than non-Aboriginal persons (Lima et al., 2006). Thus, increased rapid disease progression, including more complications, may likely happen more often to Aboriginal peoples living with HIV/AIDS, and they may subsequently die from it.

In a study by Hogg and colleagues (2002), after defining patients who receive HAART 75 percent of the time or more during their first year of therapy as being consistently treated, it was found that receiving HAART <75 percent of the time during the first year of therapy is associated with higher rates of mortality (Hogg et al., 2002; Wood et al, 2003b). Overall, among the 833 individuals who received HAART before death, only 379 (45.5 percent) received antiretroviral medication 75 percent of the time or more during their first year of therapy, and 454 (54.5 percent) received antiretrovirals <75 percent of the time. Among the 81 Aboriginal persons who accessed therapy, only 23 (28.4 percent) received HAART 75 percent of the time or more (Wood et al, 2003b). This therefore shows that those who died without ever receiving HIV treatment were more likely to be Aboriginal.

Using a hypothetical model developed in 2005, researchers estimate that by increasing HAART coverage by 25 percent over current uptake, the annual number of new HIV cases could be reduced by 37 percent. And if coverage could be expanded to include all those

currently eligible, the number of new cases could be reduced by over 60 percent (BC Provincial Health Officer, 2009; Lima et al., 2008). A more recent BC Centre for Excellence (BC-CfE) in AIDS/HIV study by Montaner and colleagues (2010) is the first to gauge economic benefits of treating more people with HAART. The study shows that increasing HAART treatment for people with HIV/AIDS would provide significant cost savings over a relatively short period of time, according to a formal economic analysis. It was demonstrated that increasing HAART coverage from the current estimated 50 percent to 75 percent of all clinically eligible British Columbians (HIV-infected individuals with CD4 cell counts below 350 cells/ul) would deliver a net benefit of 900 million US Dollars over 30 years (Montaner et al., 2010). The study concluded that, if more of those who are HIV positive are treated, fewer people will end up being infected, and this would lead to cost saving in the long run. The study's key finding shows that while expanding HAART use is cost-effective for individual patients (i.e., it has direct financial benefits for HIV/AIDS patients who have received treatment and are able to work and pay taxes, for example), the benefits become exponentially greater when HAART's ability to prevent HIV transmission is considered. Because of this potential to improve public health, expansion of HAART may be a worthwhile investment.

Understanding the factors that Influence Adherence to HIV treatment

Several studies have been conducted to shed light on the factors affecting adherence to HIV treatment. Ickovics and Meade (2002b) divide the factors associated with medication adherence into five intersecting categories: patient variables (including socio-demographic characteristics); factors related to treatment regimen; disease characterization; patientprovider relationship; and aspects of the clinical setting. Mills and colleagues (2006) classified the factors into four key themes: patient related (e.g. fear of disclosure, forgetfulness, being depressed); beliefs about medication (e.g. faith in how well the drugs work); daily schedules (e.g. disruptions to routine); and interpersonal relationships (e.g. trusting relationship with health care provider, social isolation) (Mills et al., 2006).

Medication-related Factors

HAART consists of a regimen that can include up to 20 pills a day, with multiple dosing throughout the day and specific food and fluid-related instructions (Horizons/Population Council, 2004). These are often difficult to follow for patients and contribute to poor adherence. The higher the pill burden, the lower the adherence. A greater number of anti-retroviral medications (Kleeberger et al., 2001) and a frequent dosing of three or more times per day (Eldred et al., 1998) were found to be associated with a lower level of adherence, with some patients reporting taking 'drug holidays' as a result of 'pill fatigue'.

Antiretroviral medications often have side effects, some of which are temporary, like diarrhoea, nausea and vomiting, while others may be longer lasting, like peripheral neuropathy and metabolic changes. Studies have shown that when patients experience side-effects, they tend to stop treatment or take it irregularly. It has also been shown that drug toxicity can adversely affect adherence to HAART (Chesney, 2000; Duran et al., 2001; Max & Sherer, 2000). It is also generally believed that significantly low adherence to HAART can arise from long duration treatment, with serious side effects, and potential drug interactions (Van Servellen et al., 2002).

Patient Factors

Patient factors that have been studied include: socio-demographic factors, such as gender, ethnicity, age, employment, income, education and literacy; and psychosocial factors, such as active drug or alcohol use, degree of social support, social stability, depression, procrastination and other psychiatric illnesses. Studies have found that male sex, white ethnicity, older age, higher income and higher education and literacy correlate with better adherence. Depression, psychiatric illness and active alcohol or drug use have been shown to prevent patients from adhering to treatment. However, social support helps patients adhere better (Ickovics & Meade, 2002b).

Income status.

According to a study by Schechter and colleagues (1994), slower progression of HIV infection, independent of access to health care, is associated with higher socio-economic status. Other studies also found that a higher socio-economic status prior to infection is associated with both a slower rate of disease progression and better chances of survival (Hogg et al., 1994; Strathdee, 1997).

Knowledge of resistance.

A patient's knowledge and understanding of issues related to non-adherence and resistance, as well as one's individual medication regimen, has been shown to determine adherence (Horizons/Population Council, 2004). Other studies have shown that high functional health literacy, as well as a high educational level, is associated with better adherence (Maskew et al., 2007; Van Servellen et al., 2002).

Belief and confidence.

Adherence to medication has also been shown to be determined by whether or not one strongly believes or has confidence in therapy and in oneself to be able to adhere (Horizons/Population Council, 2004). In a study from Costa Rica, Stout and colleagues (2004) found that, along with belief and confidence, the most common reasons for non-adherence were forgetfulness, missing clinic appointments, having a busy workload, falling asleep through dose time, being far from home and a change of daily routine.

Adjusting the HAART regimen by incorporating it into an individual patient's daily lifestyle and habit development is of utmost importance as it has been shown to increase adherence levels (Lewis et al., 2006). Furthermore, according to Lewis and colleagues (2006), patients that are better able to accept the trade-offs between the benefits of medication and its limitations, such as side effects, are able to more easily recognize the importance of adherence to HAART. In today's world, with the availability of resources, there is a strong preference for a once-daily dosage and compact therapy which is more likely to yield better long-term adherence and virologic suppression. However, for some on a twice-daily regimen, if a dose is missed or delayed, it is important for health-care providers to emphasize that taking a dose late, rather than omitting it, is always advisable (Conway, 2007) so as to avoid development of non-adherence.

Depression.

The prevalence of depressive symptoms among persons living with HIV has been found to be more than double that found in the general population, with studies reporting on levels as high as 34 percent (Low-Beer et al., 2000; Turner et al., 2003). Several studies indicate that depressive symptoms are associated with disease progression and death in individuals with HIV prior to the development of effective HIV anti-retroviral therapies (e.g. HAART), and since the introduction of more effective therapies the associations have been magnified (Farinpour et al., 2003; Leserman et al., 2002). In one study by Singh and colleagues (1996), depression was associated with a greater decline in CD4 counts and a trend towards accelerated mortality. These findings were attributed to both the effect of depression on the immune system and its effect on adherence. Clinical depression is associated with decreases in all of the measures of lymphocyte function (Herbert & Cohen, 1993). This is detrimental for patients who already have a low immune status due to HIV/AIDS. Other studies have

shown that early discontinuation or delayed initiation of HAART is common in those with depressive symptoms (DiMatteo et al., 2000; Leserman et al., 2002) and this may promote disease progression and increase mortality through health-related behaviours. Depression has also been shown to be closely associated with non-adherence to therapy, which in turn, is associated with both disease progression and survival (Simpson et al., 2006). Depression, however, is often a treatable illness and this makes it imperative for health care providers alike to recognize its symptoms early and initiate appropriate treatment that may lead to enhanced adherence to HAART.

Illicit drug use.

The spread of HIV among injection drug users (IDUs) has been and still is a public health emergency especially in Vancouver's DTES. There was an 18 percent annual HIV incidence rate in 1997 and an HIV prevalence rate of 35 percent among local IDUs in Vancouver alone (Kuyper et al., 2004). Evidence also suggests that IDU is the most common avenue of HIV transmission among Aboriginal peoples. Before 1993, 10.9 percent of reported AIDS cases among Aboriginal peoples were attributed to IDU. This figure increased to 58.3 percent by 2003 (PHAC, 2004), and to 58.9 percent by 2005 (PHAC, 2006; Mehrabadi et al., 2008).

According to the BC Centre for Excellence in HIV/AIDS, in 2003 one third of people who died from HIV-related causes in B.C. mostly resided in the DTES of Vancouver and did not receive essential life-saving treatment (BC-CfE, 2006). The same report also showed that the lowest life expectancy for HIV-positive individuals in B.C. is in IDUs not receiving HAART (BC-CfE, 2006). This is on the background that Vancouver's DTES is the poorest urban area in Canada and is a community characterized by high rates of HIV among IDUs. It is home to over 16,000 long-term residents and approximately 4700 of Vancouver's estimated 8000 IDUs (Wood et al., 2004).

In addition, IDU is compounded by non-injection illicit drug use as this facilitates sexual transmission of HIV. This is so because not only do IDUs have high prevalence rates, they also have high-risk behaviours, and as such remain an active source for new HIV infections (Montaner & Volkow, 2010). The most commonly used illicit drugs associated with HIV infection are heroin and cocaine (associated with frequent needle sharing) (Tyndall et al., 2001); however, the use of club drugs like methamphetamine has increased substantially in the past several years and is common among those who have HIV infection (Morin et al, 2004). Crystal methamphetamine has been shown to initiate, intensify, and prolong sexual encounters. It has also been associated with the transmission of HIV as it is linked to high-risk sexual behaviour (Halkitis et al., 2001; Semple et.al. 2002; Zule & Desmond 1999). Having said this, because of repeated use or during the withdrawal process, all illicit drugs have been associated with ailments such as depression and anxiety. According to Mayer and colleagues (2004) this is important in the treatment of HIV infection, as depression is one of the strongest predictors of poor adherence and poor treatment outcomes.

IDUs who have HIV disease present special treatment challenges because they have limited access to HIV care and are less likely to receive HAART than other populations (Gorbach et al., 2006). Factors associated with low rates of HAART use among IDUs have included active drug use, the need for, as well as the lack of, access to illicit drug treatment programs, and recent incarceration (CDC, 2003; Gorbach et al., 2006). Misperceptions about the dangers and benefits of HAART, coupled with the strong urge to keep using addictive substances, can all lead to decreased adherence (Sterk et al., 2003). The relationship between health care workers and IDUs is complicated by a dependence on, and the compulsion to keep using, addictive substances that fuels the chronic and relapsing nature of substance abuse. On a brighter note, in the case of opiate addiction, Methadone Maintenance Treatment

(MMT) is available. Methadone is an orally administered, long-acting opiate agonist which, when used, has been shown to be effective at preventing HIV infection among people who are retained in MMT programs (Gibson et al., 1999). Methadone is associated with decreased heroin addiction, decreased needle sharing, and improved quality of life (DHHS, 2009). Some studies have also shown that drug use within methadone maintenance programs is associated with other health behavioural patterns, such as following the antiretroviral treatment schedule (Hernández et al., 2009; Palepu et al., 2006). However, other research has also shown that some patients, especially the marginalized, believe that MMT services, if and when provided, are of a lower standard of care than those that other groups of patients receive (Parkes, 2009).

One may wonder whether the first step in provision of care and treatment for IDUs should be the recognition of the existence of a substance abuse problem. Whereas this is often open and obvious, patients may hide such behaviours from clinicians. On the other hand, it is worrying that HAART is often withheld from IDUs infected with HIV based on the belief that their unstable lifestyles, and the multiple social, medical, and economic challenges they typically face, would either make them unable to adhere to HAART or may predetermine a markedly inferior outcome with HAART. According to Lert and Kazatchkine (2007), this would compromise treatment effectiveness and promote HIV drug resistance. Some reports have demonstrated that because of issues of social instability related to illicit drug addiction (Chander, 2006), HIV-infected IDUs may not be deriving the full benefits of HAART (Lert & Kazatchkine, 2007). For instance, prior studies have shown that IDUs are less likely to be prescribed HAART (Bruce & Altice, 2007; Wood et al, 2003b), and a recent international collaboration demonstrated that a history of injection drug use was an independent predictor of worse outcome with HAART (Egger et al, 2002). Such reports may have contributed to an increasingly prevalent belief among clinicians that IDUs may be significantly less likely to benefit from HAART (due to treatment failure or development of resistance), and prior studies have shown that clinicians commonly withhold HAART from IDUs (Ding et al, 2005; Loughlin et al, 2004; Maisels et al, 2001). Also worrying is that some studies have shown that the refusal or failure to treat HIV-infected patients is partly associated with a lack of belief by health care providers in an ethical responsibility to treat patients with HIV when clinically indicated (McCarthy, Koval & MacDonald, 1999).

However, in a recent study of antiretroviral naive HIV-infected patients in a provincewide HIV/AIDS treatment program in British Columbia, IDU was not associated with decreased survival among HIV-infected patients initiating HAART (Wood et al, 2008). In fact, after adjusting for adherence, IDUs and non-IDUs had the same health benefits including a comparable 5-year survival when receiving HAART (Wood et al, 2008). HAART regimens may therefore have effectiveness at a population level that is not significantly different regarding the survival of individuals with and without a history of IDU. The literature also indicates that, when IDUs are not actively using drugs, efficacy of HAART in the IDUs is similar to that seen in other populations (Copenhaver et al, 2003). Furthermore, HAART therapeutic failure in this population generally correlates with the degree that drug use disrupts daily activities rather than with drug use (Hartel & Schoenbaum, 1998). Those with a history of prior drug use should therefore be given HAART since they have adherence rates similar to non-drug users. One can also argue that, HAART should be initiated at higher CD4 levels because many substance users will have co-morbid conditions, for example e.g., chronic hepatitis C or B infection, that may favour treatment (Montaner & Volkow, 2010). These facts should help to challenge the common belief that IDUs may be, to a large extent, less likely to benefit from HAART. However, it should also be noted that, although many

IDUs can sufficiently control their drug use over long enough periods of time to benefit from care, substance abuse treatment is often necessary for successful HIV management (DHHS, 2009). In light of this, the provincial government of BC organized an interagency consultation to review the state of the art and generate recommendations regarding the management of HIV infection in substance users (Ministry of Health Services, 2010; Montaner et al., 2010). These recommendations emphasize the urgency of seeking (proactively identifying substance users), testing (annually, per CDC recommendations), treating (using HAART, per current guidelines), and retaining (through optimal treatment of the substance-use disorder) HIV-infected users (Montaner & Volkow, 2010). It however remains to be seen how this will all pan out in practice.

Alcohol use.

A major concern with alcohol use in HIV-infected people is the impact it has on HIV medication adherence. Alcohol use is prevalent among HIV-positive individuals (Bryant, 2006; Conigliaro et al., 2006) and its use has been frequently linked with poor adherence (Chandler, Lau, & Moore, 2006; Parsons, Rosof, & Mustanski, 2007; Sankar et al., 2007). One meta-analysis revealed that HIV-positive individuals who abstain from alcohol are approximately 50 percent more likely to be adherent to their HAART than those who drink alcohol (Hendershot et al., 2009). The amount an individual drinks is also associated with an increased risk of poor adherence. Adherence to HAART is progressively compromised as drinking levels increase (i.e., a "dose-response" effect). This is more so than the decrease in adherence associated with frequency of drinking (Hendershot et al., 2009). A study by Cook and colleagues (2001) found reports of missing doses of antiretroviral medications or to taking them off schedule, attributing missed doses to forgetting, running out of medication, or consuming alcohol or drugs were more likely in heavy drinkers. Heavy alcohol use

("binge" drinking) is defined as consumption of five or more drinks on a single occasion (National Cancer Institute, 2002). The association between heavy alcohol use and adherence is worrying especially for the Aboriginal population. Indigenous alcohol users have been shown to have a higher prevalence of heavy drinking on a weekly basis than among non-Indigenous alcohol users (First Nations Centre, 2005).

Historically, in Aboriginal tradition, alcohol was associated with loss of tradition and an out-of-balance lifestyle (Reading, 2010). According to Wardman & Quantz (2005), among other reasons, people took part in binge drinking as a way to numb the pain caused by physical and sexual abuse, low self-esteem, loss of culture and identity. On a good note however, those who stayed sober did not seek formal treatment but were motivated by renewed spirituality and their engaging in cultural traditions.

It is also important to note that, not only does alcohol consumption affect adherence, it has also been shown to have a deleterious impact on immune function as it affects markers of immunological functioning and viral suppression (Chander et al, 2006; Samet et al, 2007). However, there is hope both for today and the future because alcohol use is a modifiable behaviour and, as such, successful alcohol interventions could improve adherence to HAART and delay disease progression (Parsons et al., 2007; Samet et al., 2007).

Forgetfulness and oversleeping.

Forgetfulness has been shown to be associated with poor adherence to HAART (Ostrop, Hallett, & Gill, 1998; Weidle et al., 1998). It however does not usually occur in isolation and is attributed to many causes. Forgetfulness may be due to memory deficits and can also be secondary to emotional stress (Laws et al., 2000).

Some studies have also associated low adherence to HAART to a distorted sleep pattern (Golin et al., 2002; Reback, Larkins, & Shoptaw, 2003). Patients may find it difficult to

balance their needs to eat, work, be involved in social activities, and sleep against their need for HAART. Sleepiness can also be secondary to HIV itself or comorbid conditions. A distorted sleep pattern is also common in those who are homeless where it may lead them to patients sleeping through medication time (Laws et al., 2000; Wolitski et al., 2007).

Both forgetfulness and oversleeping have been associated with use of illicit drugs as well as problem drinking (Reback, Larkins, & Shoptaw, 2003). Such patients may find it difficult to maintain a schedule, keep track of time, eat and drink on a regular basis, and do other daily life routines and, therefore, their adherence to HAART during drug use may be erratic. According to Reback and colleagues (2003), those taking methamphetamine, for example, can be awake for extended periods of time and then sleep for up to 24 hours.

Procrastination and being too distracted or busy.

Studies indicate that procrastination and being too distracted or busy can lead to low HAART adherence (Hill, Kendall, & Fernandez, 2003; Powell-Cope et al., 2003; Westerfelt, 2004). One may procrastinate or be too busy or distracted due to work and/ or because they are searching for money to buy daily needs, among other reasons. One may put off taking their medication because of anxiety regarding food availability or due to being depressed in the face of low food access (Che & Chen, 2001). To make this worse, among the HIV-infected, food insecurity itself has also been associated with incomplete viral suppression (Weiser et al., 2009) either secondary to decreased health services usage (Hadley & Patil, 2008) or due to postponing needed medical care (Kushel et al., 2006) that includes HAART.

Patient-provider Relationship and Clinic Setting

The patient-provider relationship and specific characteristics of the health care setting play an important role in improving adherence to HAART. There is a documented improvement in adherence attributed to one's trust and confidence in health care providers (Van Servellen et al., 2002). Patients who perceive themselves as more engaged with their health care provider have been shown to report better treatment adherence (Demmer, 2003). This may be because the health care providers, in their extended interaction with patients, have taken time to understand the patient's difficulties and thus developed trust (Altice et al., 2002; Schneider et al., 2004). Aspects of the clinical setting may also be associated with improved adherence. A friendly, supportive and nonjudgmental attitude of health care providers, convenient appointment scheduling and confidentiality contribute to better adherence.

Adherence can also be promoted by a culturally competent health care service that would provide services and information in languages as required, do so at appropriate comprehension levels, frame information in the context of an individual's cultural and belief practices, and be willing to listen and learn from members of the culture (Chin, 2000; Jackson, 2008). However, it is important to recognize that diverse languages can pose significant challenges in urban areas where programs are developed to support First Nations, Inuit and Métis people alike (Canadian Aboriginal AIDS Network [CAAN], 2002). A barrier to appropriate care may therefore be based in mismatches of linguistic and comprehension bases (Chin, 2000).

Disease Characteristics

A history of opportunistic infection and more advanced disease or symptom severity (Bond & Hussar, 1991) and low CD4+ counts (Erlon & Mellors, 1999) contributes to increased adherence. Patients who have had serious opportunistic infections may see their illness to be severe and be motivated to adhere better to their treatment (Singh et al., 1996). This is in line with the health belief model for treatment adherence which emphasizes that the most important determinants of adherence are patients' beliefs and perceptions of the illness

itself. According to this theory, most people will not attempt to treat or prevent a condition unless they consider themselves as vulnerable or susceptible to the disease or its consequences or actually have the disease, and believe that treatment will be beneficial or effective in preventing or reducing the susceptibility and/or severity of disease (Eraker et al., 1984; Moore et al., 1994; Rosenstock et al., 1994). Asymptomatic individuals may also perceive themselves as less vulnerable to future complications and may therefore be less motivated to comply with recommended treatment (Ickovics & Meisler, 1997; Jones et al., 1999; Singh et al., 1996). On the other hand, for some patients, seeing an improvement in the immune and virologic indices used to monitor HAART (T-cells and HIV viral load) may encourage them to maintain adherence (Pratt et al., 1998). Furthermore, acknowledging the role of medication in avoiding illness and death, having a strong belief in the efficacy of one's medication have been reported to contribute to the facilitation of high adherence (Lewis et al., 2006). A given patients' own perceptions, beliefs, and expectations concerning their illness and its treatment are therefore important aspects that need to be assessed and determined in order to inform possible interventions directed towards the reinforcement of appropriate beliefs that enhance compliance.

Another important aspect to consider is that persons with HIV/AIDS can also present with symptoms of memory loss secondary to damage to cells in certain sections of the brain. Memory impairment in people with HIV often occurs early in their 20 - 40s (Lynn, Newton, & Rae-Grant, 2003) and this may impair adherence to HAART (Meyerhoff, 2001). Pin-pointing which memory symptoms may be specifically related to HIV infection (as opposed to Alzheimer's disease, depression, or drug related causes) is still challenging, however, because of the increased survival and aging of those living with HIV/AIDS. Therefore,

numerous age-related causes of memory impairment may need to be ruled out through thorough assessment (Selnes, 2005).

Other Factors

Poverty.

The poor are exposed to greater personal and environmental health risks, are less well nourished, have less information and are less able to access health care; they thus have a higher risk of illness and disability. Conversely, illness can reduce household savings, lower learning ability, reduce productivity, and lead to a diminished quality of life, thereby perpetuating or even increasing poverty. Poverty is often defined in absolute terms of low income, for example, less than US\$2 a day, and relative poverty is said to exist when the household income is less than the national average income (WHO, 2008/2010). According to Statistics Canada (1999), relative poverty is usually synonymous with the terms "low income" and "poor/low socioeconomic status" and is measured using Low-Income Cut-Offs (LICOs). In reality however, there's a problem of defining poverty and the consequences of poverty exist on a relative scale. Poverty is also said to exist when people lack the means to satisfy their basic needs (American Psychological Association [APA], 2010). In this context, the identification of poor people first requires a determination of what constitutes basic needs. Whether one sees them as those necessary for survival or as those reflecting the prevailing standard of living in the community can be a point of debate. Hence, one needs to decide on what criteria to use for levels of basic need. Regardless of this, the problem of definition is further compounded by the noneconomic, and sometimes negative, connotations that the word poverty has acquired. Poverty has been associated, for example, with high rates of disruptive or disorderly behaviour, and improvidence. Whatever definition one uses, it is commonly assumed that the effects of poverty are harmful to both individuals and society.

An association, be it indirect, remains between poverty and the rate of HIV infection and this can be described by several factors like poor nutrition, lack of access to health care and having limited resources in meeting basic needs (Barnett & Whiteside, 2006). Furthermore, it has been shown that people who have a higher income have less difficulty when adhering to treatment than those in poverty (Nakiyemba et al., 2006) and that poverty creates emotional distress, limits social interaction and damages health (Grierson, et al., 2006). What is worrying about these associations is that, in Canada the urban Aboriginal population is significantly disadvantaged compared to their non-Aboriginal counterparts, the former group being more likely to live in poverty than the latter (Reading, 2010). It has to be said however that, poverty relief may not stop HIV/AIDS, but raising individuals and communities out of poverty may enhance their capacity to resist HIV/AIDS once infected. Again, free treatment, as is the case in BC, may not be enough if HAART programs do not adequately address poverty.

Nutrition and dietary restrictions.

According to a UNICEF report (2010), HIV/AIDS can increase the risk of food and nutrition insecurity and conversely, food insecurity can increase vulnerability to HIV infection and also promote the progression from infection to illness. This is because HIV/AIDS results in reduced food intake and inefficient utilization and/ or loss of nutrients by the body, while simultaneously increasing the nutritional needs (energy and protein requirements) of people living with HIV/AIDS because the body has to fight the virus and opportunistic infections (Macallan, 1999). Not only do HIV/AIDS patients need extra nutrition (Kotler, 2000), they also have an added nutritional need during the initial stages of treatment as the body regains strength and weight (Au et al., 2006). To complicate this, repeated infections and fatigue may often result in poor appetite, leading to further loss of

nutrients in the body (Nakiyamba et al., 2006). Furthermore, malabsorption and other digestive problems associated with HIV/AIDS result in protein loss and a secondary breakdown in muscle tissue (Macallan, 1999). Proper nutrition can therefore help strengthen the immune system and slow down the progression of the illness. Addressing nutritional needs may be critical to those who are on HAART. The challenge is that of linking each individual on HAART to a support mechanism that would ensure the availability of food at a convenient time on a daily basis (Hardon et al., 2007).

Dietary conditions may add to the complexity of adherence to HAART as an adjustment to one's lifestyle is often required. Patients can find their meal schedule difficult to follow due to some medications that require dosing while fasted (Grierson, et al., 2000). Difficult or complicated medication regimens may be difficult to adhere to if one has travelled without their medication (Castro, 2005). The physical characteristics of a given medication (e.g., taste) may also affect a patient's ability to be adhere (Crespo-Fierro, 1997).

Housing.

Access to safe, affordable housing helps people living with HIV/ AIDS and marginalized people to follow medical and drug treatments, which lower viral load and reduce the risk of transmission (Holtgrave & Curran, 2006). Housing is essential to their long-term stability (BC Minister's HIV/ AIDS Advisory Committee, 2000). It is worrying therefore that most Aboriginal people are at an increased risk of becoming homeless as they are already socioeconomically disadvantaged (Helin, 2002). Homelessness and inadequate housing make it more difficult for people to manage and live with HIV/AIDS. Homelessness contributes to non-adherence to HAART (Wolitski et al., 2007) and is associated with several risk factors for non-adherence. High levels of social isolation and low levels of social support are seen in homeless Aboriginal people (Reading, 2010). Because of being homeless, they are more

likely to use illicit drugs and alcohol as a means of coping with illness, trauma, or pain, and to relieve isolation than stably housed persons (Aidala et al, 2005; Kidder et al, 2008). Without secure housing therefore, people do not have the stability required to maintain their treatments or their pharmacological regimens. The harsh daily realities of homelessness and the legacy of historical trauma can lead to immediate and ongoing distress and may well compromise one's interest in changing behaviours and pursuing, receiving and sustaining treatment.

Stigma and discrimination.

People living with HIV/AIDS often encounter stigma and discrimination and this affects their ability to take up care, treatment and support (CAAN, 2004). Most of the people living with HIV experience an overwhelming burden of stigma because they have become infected through a behaviour that is stigmatized (injection drug use [IDU], gay), belong to a culture (Aboriginal), or social class (poor) that is vulnerable to stigmatization. The stigma and discrimination experienced by patients within health services varies depending on the social and environmental context in which care is provided. However, the physical layout of a facility or organization could contribute to stigma, particularly if confidentiality cannot be assured.

According to Matiation (1999), discrimination plays a huge role towards the burden of HIV/AIDS on Aboriginal communities. Because of this, it is imperative to approach any discussion on discrimination and HIV/AIDS in Aboriginal people with a full understanding of the often untold history of oppression, cultural disintegration, racism, and colonialism. The discrimination can be experienced by Aboriginal people in their day to day lives both in the healthcare system and on the street. The anger that Aboriginal people feel as a result of their discrimination may be internalized, resulting in a high degree of self-destructive behaviours

adding to a higher risk of HIV transmission and to low adherence levels to HAART.

A positive, trusting relationship with health care personnel is fundamental to the provision of non-discriminatory care. Knowledge of the phenomenon of AIDS stigma is important for health professionals because of its serious consequences: stigma has the potential to limit prevention efforts (Campbell et al., 2005); stigma may act as a barrier to diagnosis and appropriate treatment (Link & Phelan, 2006; Rintamaki et al, 2006); and stigma may induce psychological stress and result in an unwillingness to access health services (Des Jarlais et al., 2006). Stigma and discrimination can therefore be major barriers to effective HIV prevention and AIDS care. Because of this, addressing the ways in which stigma intersects with HIV/AIDS is therefore important (Larkin et al., 2007).

Social support.

A diagnosis of HIV places a substantial amount of burden and stress on both the infected and the affected, and carries many painful psychosocial consequences. One key psychosocial consequence is that of social isolation. Those with an HIV/AIDS diagnosis have been shown to spend considerable amounts of time in solitude (Simoni et al., 2000). Others shy away from fellow HIV/ AIDS patients, leaving themselves vulnerable to overwhelming emotional responses requiring social support in order to cope (Kalichman et al., 2003). Although the most frequent social facilitator to adherence includes help from others, and with the fact that social support is very often needed, some HIV/AIDS patients are still scared to disclose their status for fear of discrimination.

Social isolation can serve as a hindrance to adherence and is predictive of decreased adherence to HAART (Altice et al., 2001). Usually, most patients who report adherence to treatment regimens also report greater social and emotional support from their health care providers and significant others (Morse et al., 1991). Conversely, adherent patients have been found to be those who live with others, have a partner, social or family support, engage in peer interaction, and have better physical interactions and relationships (Lewis et al., 2006). Having a confidant and receiving instrumental support are significantly correlated with reduced HIV stigma (Emlet, 2006). However, patients who do not have adequate social support and are pessimistic about treatment effectiveness remain highly vulnerable to becoming non-adherent to treatment (Diabate et al., 2007).

Social support networks being the most widely available psychosocial intervention for HIV/ AIDS patients (Walch et al, 2006) can be a powerful source for empowerment for those living with HIV/AIDS and on HAART. The added advantage is that some patients may even become very useful in assisting others as they become experts in the latest treatment options/ combinations thereof (Nachega et al., 2006), and even experts of services available.

Using support networks and a community outreach programs approach to HAART adherence may be a more cost-effective and acceptable way to deliver therapy. Support groups incorporating those peers who can provide both the delivery of the HAART, as well as constant cognitive reinforcement and social support, may prove very useful to increasing adherence.

Medication adherence and outcomes for persons with HIV/AIDS have been reported to be substantially better with outreach intervention (Berrien, 2004). Intervention through home visits by experienced health care providers can improve knowledge and understanding of HIV infection, identify and resolve real and potential barriers to medication adherence, and ultimately improve adherence. More widespread use of supervised care, especially for IDUs, could contribute to improvement in adherence rates.

Counselling to improve adherence to HAART has been shown to increase length of life and modestly reduce HIV transmission (Zaric et al., 2008). The same study by Zaric and colleagues (2008) also showed that counselling can provide significant benefit for individual patients, where there are limited resources, at an affordable cost. Since the level of adherence to HAART may also depend on the person's ability to adapt to and manage emotional and psychological difficulties in relation to their illness, counselling can therefore also play a vital role in patients as part of the provision of care and support. Counselling can take various forms but with a common goal of providing information to and thus improving the patient's understanding about the disease and its management, medication, diet and life style modifications, and assisting patients in clarifying the doubts and in taking suitable decisions with respect to the disease management. Offering patients advise on an individual case basis and tailoring medication regimen to one's lifestyle has been shown to have considerable impact in improving adherence in those on HAART (Sall, 2002).

With respect to HAART, adherence counselling is necessary but not a one-off occurrence. Patients often experience treatment fatigue and may simply stop taking medication as a result. They may also stop taking their medication when they start feeling better (Van Dyk, 2008). Recounselling, with emphasis of the importance of 100 percent HAART adherence, on a regular basis can therefore, be extremely important. Substance abuse counselling is another important aspect that, when applied, should supplement efforts to improve adherence to HAART (Gorbach et al., 2006; Sankar et al., 2007).

Availability of funding and services/programs.

The availability of funding and services/programs can improve adherence to HAART since with more funding comes more sustainable programs and services for people to access. This may not be the case for the Vancouver DTES, particularly the VNHS clinic, where medical facilities are often under resourced and continued lobbying for funding is the order of the day. Studies have shown that tied with lack of funding and resources, a lack of staff

can lead to an increased workload, burnout, low staff moral and absenteeism (Van Dyk, 2008). All this may lead to decreased quality of care for HIV/AIDS patients in the long term and ultimately affect adherence to HAART.

Having said this, it should be noted that, according to AVERT, an international HIV and AIDS charity, some stigmatized and marginalized groups, such as IDUs, are sometimes denied funding by some donors (AVERT, 2010). The charity argues for funding to be provided to community organizations, well versed with local knowledge and skills, in order to improve adherence levels to HAART as well as to curb HIV and AIDS in the long term (AVERT, 2010).

Summary

In this chapter the salient literature relating to the residential school legacy and indices relating to HIV/AIDS in relation to Aboriginal people were presented. The drug treatment program, as well as access to and discontinuation of HIV treatment, was reviewed in order to provide an understanding of the management of the illness in BC. Finally, factors that influence adherence to HIV treatment were presented.

In the next chapter the methodology used in the collection and analysis of the data is presented.

CHAPTER THREE

Methods and Methodology

Introduction

In this chapter the methodology used in the collection and analysis of the data is discussed. This includes information regarding the research paradigm that has been utilised, the setting, the sample, the procedure and ethical considerations, data collection and the analysis of data.

Research Paradigm – The Phenomenological Approach

A qualitative research paradigm underpins this study. According to Cresswell (2007), a qualitative study is an inquiry process based on the constructing of a complex but holistic picture formed with detailed views of participants, and conducted in a natural environment in order to help understand a social or human problem. The need to understand matters from the participant's perspective is therefore the basis of the decision to use the qualitative paradigm. Using this paradigm, each participant's own interpretations of reality is valued. These socially constructed yet individual interpretations are each unique and rich in context and cannot be taken apart and generalized to the population at large (Searle, 1995).

The aim of this research is to investigate the determinants of adherence to highly active anti-retroviral treatment (HAART) in Aboriginal men in the Downtown Eastside (DTES) of Vancouver. The objectives are to investigate the determinants of adherence to HAART in Aboriginal men in the DTES of Vancouver; compare the effects of the determinants and offer recommendations to improve adherence to HAART in Aboriginal men in the DTES of Vancouver; assess the effects of historic trauma/residential schools on HAART outcomes in Aboriginal men in the DTES of Vancouver; and, to offer culturally-sensitive recommendations to better address the effects of the determinants and/ or unresolved pain, aimed at improving access to HAART among Aboriginal men and reducing deaths due to HIV/AIDS. Using the qualitative research paradigm therefore, I made every attempt to understand the worldview and belief systems of the participants.

A phenomenological methodology has been used in this study as its main task is to investigate phenomena, including the nature of human experience, in the way these phenomena appear "in their fullest breadth and depth" (Spiegelberg, 1965, p. 2); to describe the way things appear, or particular phenomena, as lived experience (Speziale & Carpenter, 2007). The purpose of phenomenology is, therefore, to describe the lived experiences of people, and the documentation of that experience should be done in such a way that it is true to the lives of the people described (Anderson, 1991). Lived experiences are those influenced by internal or external forces but involve conscious life events before both reflection and interpretation (Penner & McClement, 2008). Phenomenology is therefore suited to this study precisely because it is only those who have lived with HIV/AIDS and have been on HAART that can tell the story of their lived experiences, and only they are the experts in telling this story. This lived experience is what is true or real in one's life and, as such, gives meaning to how a phenomenon is perceived by that individual (Giorgi, 1997).

This study utilized the methodological approach of the Vancouver School of Doing Phenomenology developed at the University of British Columbia in Vancouver by Professor Joan M. Anderson (Anderson, 1991). The Vancouver School of Doing Phenomenology is a blend of description, interpretation, explication, and construction to describe the phenomenon experience (Anderson, 1991) and is aimed at increasing the greater social good by explication of human experiences. This phenomenological approach, in its examination of subjective human experience, is good at surfacing deep issues and making voices heard. I thus sought to understand the reality of others while allowing the participants to guide the process. Most phenomenological researchers agree that there is need for the seeking of rich and complex descriptions of a phenomenon to arrive at the correct meaning of any given lived experience (Finlay, 2009; Wertz, 2005). It should however be noted that there is no universal theory or approach to which all phenomenologists subscribe. Furthermore, the qualitative method used is sometimes disconnected from the statement of the philosophical foundation that guides the method (Stubblefield & Murray, 2002). In some phenomenological research, the application of philosophical ideas to a given project may come with uncertainty. Choosing the right methodology was therefore a daunting task. In line with a recommendation by Koch (1995), I therefore appraised the philosophical underpinnings of the original fields of phenomenology before choosing the blend of phenomenology used in this study.

Two Phenomenological Frameworks

The two main phenomenological frameworks are descriptive (Husserlian) and interpretive (Heideggerian) phenomenology (Cohen & Omery, 1994; Lopez & Willis, 2004). In both, there is the assumption of readiness upon the researcher to listen to the participants descriptions of the lived experiences. They both bring out knowledge that reflects insights into the meaning of the studied phenomena.

There are, however, a few important differences; two of which are in how the findings are generated and in how the findings are used to augment knowledge. Firstly, the interpretive approach (i.e., Heidegger-inspired) does not negate the use of a theoretical orientation or conceptual framework as a component of inquiry. A distinct textual representation of the phenomenon under study is therefore produced as the researcher interprets and uncovers meanings through application of prior knowledge and insights (Kleiman, 2004). Secondly, personal experiences and prejudices of the researcher are important to the resulting

interpretation as they are considered as strongly influencing the understanding of the phenomena (Dowling, 2004). "The meaning of phenomenological description as a method lies in interpretation," (Heidegger, 1962, p. 37). Heidegger articulated the concept of co-constitutionality (Koch, 1995) that holds that the resultant meanings are a combination of the meanings articulated by both researcher and participant in the study (Lopez & Willis, 2004).

In contrast, in the descriptive method (i.e., Husserl-inspired), the researcher makes no interpretations. Rather, the participant's descriptions are analyzed and divided into meaningladen statements, gathering those meanings that are essential to the construct of the phenomenon of interest being studied. This approach is used when little is known about an issue with the objective of both understanding and making clear the meaning of a phenomenon under study from the participant's perspective (Giorgi, 1997). Descriptive phenomenology employs a process of reduction, where knowledge is not held with judgment, but in its purity, complexity, and richness as it is received (Dowling, 2007), and thus the essence of the phenomena is allowed to emerge. Researchers only make declarations which are supported by appropriate validations (Giorgi, 1986) based on pure, untaught, noninferential knowledge. In order to eliminate the influence of inherent biases and preconceptions of the researcher from the study, these are bracketed or set aside (Lopez & Willis, 2004). With respect to bracketing, it involves a process whereby "one simply refrains from positing altogether; one looks at the data with the attitude of relative openness" (Giorgi, 1994, p. 212). According to Ashworth (1996) and Finlay (2009), bracketing involves setting aside, throughout the research process, any presuppositions about scientific theories, knowledge and explanation, any claims by participants about the validity of information, and the researcher's personal views and previous experiences (Ashworth, 1996; Finlay, 2009).

The Vancouver School of doing Phenomenology

The Vancouver School of Doing Phenomenology is a blend of description, interpretation, explication, and construction developed at the University of British Columbia by Professor Joan M. Anderson (Anderson, 1991). Since its development, the method has proved to be a methodology that can lead to systematic interpretation of human experiences (Halldorsdottir, 2000) as it holds that data in any study do not speak for themselves as such. The researcher must make sense of the data in a meaningful way together with research participants who are seen as dialogue partners or co-researchers. The researcher must be ready to think beyond preconceptions and see the world afresh through the co-researcher's eyes.

The Vancouver School of Doing Phenomenology restores meaning which is seen as being offered to the researcher in the form of a message. It is animated by faith, by a willingness to listen, and is characterised by a respect for each participant in the study, who is seen as a truth-telling co-researcher or dialogue partner (Halldorsdottir, 2000; Ricoeur, 1990). It is assumed that their data will not be contaminated or biased by the full participation of the participants. The researcher comes open-minded to the co-researcher, who is an expert in his lived experience (Halldorsdottir, 2000). In The Vancouver School, therefore, there is respect for the dialogue partner or co-researcher as a fellow human being and his or her lived experience rather than respect for the phenomenon as such. The methodology also recognizes that, in order to be as open as possible and ready to hear something new and to truly take in what the dialogue partner is saying, it is important to lay aside, as much as possible, preconceived ideas about the phenomenon being studied. The Vancouver School also recognises that it is impossible to be totally free of preconceived ideas. It is possible, however, to bring them into view (e.g., by using a reflexive journal) which is, in itself, a technique to increase trustworthiness of qualitative studies (Lincoln & Guba, 1985). Such a reflexive journal is a diary in which a researcher on a daily basis, or as needed, records a variety of information about his/her own reflection and methodology.

The research process in the Vancouver School of Doing Phenomenology is a cyclic phenomenon encompassing a 12-step process employed in producing and analysing data (see Table 1). The steps, according to Halldorsdottir (2000) are: (1) selecting the dialogue partners (the sample); (2) first, there is silence (before entering a dialogue); (3) participating in a dialogue (data collection); (4) sharpened awareness of words (data analysis); (5) beginning consideration of essences (coding); (6) constructing the essential structure of the phenomenon for each case (individual case constructions); (7) verifying the single case construction with the co-researcher; (8) constructing the essential structure of the phenomenon from all the cases (metasynthesis of all the different case constructions); (9) comparing the essential structure with the data; (10) identifying the over-riding theme which describes the phenomenon (interpreting the meaning of the phenomenon); (11) verifying the essential structure (the findings) with some research participants; and, (12) writing up the findings (Halldorsdottir, 2000, p. 57).

Table 1

The Vancouver School of Doing Phenomenology - 12 step process

	
First there is silence	Before entering a dialogue
Selecting dialogue partners	Selection of co-researchers
Participating in a dialogue	Data collection
Sharpened awareness of words	Data analysis -Deconstruction
Beginning consideration of essences	Coding
Identifying the essential structure of the	Construct of an analytic framework of the
phenomenon in each transcribed dialogue	phenomenon
Verification of the analytic framework with	Verification of the single case construction
the relevant research participants	with the co-researcher
Identifying essential structures of the	Construction of an analytic framework of the
phenomenon of the study	phenomenon
Compare the essential structure with the data	
Identifying the over-riding theme which	Interpreting the meaning of the phenomenon
describes the phenomenon	
Verifying the essential structure of the	
phenomenon with research participants	
Writing up the findings	

Setting

This study was conducted in Vancouver. Vancouver (population 578,040) is a British Columbian city with cosmopolitan features and an estimated Aboriginal population of 11,145 (Statistics Canada, 2008). The sample was primarily drawn from the Vancouver Native Health Society (VNHS) clinic which is in the Downtown Eastside (DTES) of Vancouver. The clinic was first established in 1991 in a small storefront space. It has grown over the years and currently offers medical care seven days a week. The clinic has over 19,000 patient visits per year. The number of HIV positive patients on HAART at the VNHS clinic has risen from 294 (53 percent Aboriginal) in 2007-2008 to 349 (57.6 percent Aboriginal) in 2008-2009. This number stood at 403 at the beginning of 2010 (VNHS, 2010). The VNHS clinic clients mostly reside in Vancouver's poorest neighbourhood with the city's lowest level of income and education rates, and highest rates of health service utilization and hospitalizations.

Although it cares for many non-Aboriginal patients, it is the only clinic in the Downtown Eastside that specifically focuses on the needs of Aboriginal peoples (VNHS, 2010). The VNHS clinic also employs a multitude of physicians, nurses, and other health professionals. It also offers students practicum and volunteer positions, one of which I was honoured to occupy for seven months prior to beginning this study.

The clinic's main purpose is to improve and promote the physical, mental, emotional, and spiritual health of individuals, focusing on the Aboriginal community residing in greater Vancouver. The clinic's vision is to be a multidisciplinary comprehensive care clinic that effectively responds to the needs of the Aboriginal and non-Aboriginal community, as well as being a centre for medical education and innovation (VNHS, 2010).

Sampling

Step 1 - Selecting Dialogue Partners

The CIHR Guidelines for Health Research Involving Aboriginal People (2007) were followed in the development and conduct of this study. The first step of the Vancouver School of Doing Phenomenology was used for sampling. The study involved HIV – positive Aboriginal men from the DTES of Vancouver in BC, particularly, those who attend and/ or are serviced by the VNHS clinic. The design was flexible as it could accommodate any number of subjects. For this study however, to achieve data saturation i.e., when new categories, themes or explanations stop emerging from the data (Marshall, 1996), a sample size of ten participants (N=10) was used for the in-depth interviews. To achieve this, data review and analysis was done in conjunction with data collection.

Recruitment was mainly through collaboration with the VNHS, and the non-random methods of purposive sampling and snowballing as described by MacNealy (1999). The intention of this study was not to yield generalizable data, but rather to gain an in-depth understanding of the participants' perspectives. A *purposeful* sample is one having "the characteristics . . . necessary to answer questions about a certain matter or product" (MacNealy, 1999, p. 157). Purposive sampling groups participants according to preselected criteria relevant to a particular research question. In this case, the eligibility criteria for interviews were: HIV – positive Aboriginal males who are more than 25 years of age [Statistics Canada (2006), Age Categories - Adults], are currently, or have previously been, on HAART and are able to communicate in English. Apart from looking for participants who possessed these qualities, I considered the aim of the research and selected samples accordingly (Coyne, 1997), choosing participants likely to provide the most information in relation to the objectives specific to this research based my judgment and in consultation with

staff at the VNHS clinic. In purposeful sampling, the most important guiding principle is maximum variation. Therefore, I sought to include people who represented the widest variety of perspectives possible within the range specified by their purpose (Higginbottom, 2004; Marlow, 2005). I included participants who not only used the services at VNHS but also volunteered or worked as part of the staff as trained co-researchers or counsellors. Their experiences intersected with both having the experience of working with people on HAART as well as having a personal experience with HAART. Going one step further, the sample also included people with varying levels of education and experience. By including this range of participants it was hoped that a more holistic and in-depth data set would be obtained.

MacNealy (1999) defined a *snowball sample* as "the population of interest [that] cannot be identified other than by someone who knows that a certain person has the necessary experience or characteristics to be included" (MacNealy, 1999, p. 157). Through snowball sampling, participants, with whom contact had already been made, used their social networks to refer me to others who could potentially participate in or contribute to the study (Patton, 2002). Snowballing was done deliberately to avoid homogeneity, so that not only those serviced consistently by the VNHS clinic were interviewed. I acquired three participants this way. I also sought the help of Aboriginal peer researchers from within the VNHS to assist in recruiting participants and organizing interviews and the focus group. During the course of the study I engaged in informal conversations with Aboriginal men and attended functions relevant to historical trauma and/or HIV/AIDS (for example, the newly-formed men's group) at the VNHS clinic in Vancouver. The interaction provided opportunities to approach, hand out information sheets, and recruit interview participants. My continued presence at events ensured that participants were able to decide whether to take part in the study from an already established relationship of trust. I recruited five participants in this way. In the demographic presentation for this study, participants are referred to by number only. For example, the first participant interviewed is 001. In total, 22 respondents were recruited. The average age of respondents was 47 years, although ages ranged from 39 to 56. The year of HIV diagnosis for patients ranged from 1987 to 2008. Most respondents were taking three antiretroviral medications once a day and only two respondents were on a threein-one once a day pill. The length of time patients had been taking their antiretroviral medication regimen ranged from 2 to 14 years, with the average length of time being 7 years. Table 2 provides a composite overview of this information.

All the respondents had seen by the doctor during the past 12 months and more than half had seen either the social worker or nurse, with less than 50 percent seeing the dietician, mental health counsellor (five of the participants were currently on antidepressant medication and four were currently using illicit drugs) or having visited the hospital emergency department. Table 3 provides a composite overview of this information.

Sixty-eight percent of the respondents were either single or separated, and 27 percent were married or co-habiting. 64 percent of participants stated that they were currently living in subsidized BC housing, 27 percent were living temporarily in a hotel room, and only one respondent was living in his own house. However, none of the respondents had no fixed abode (i.e., not having a fixed geographical location as their residence) or lived on the street. Only six (27 percent) respondents had completed at high school education while the rest had some high school or less education. Fifty percent of respondents were on disability allowance, 22 percent were employed seasonally, 18 percent were unemployed, 10 percent worked part time, and none of the respondents were employed full time. Table 4 provides a composite overview of this information.
Participant responses to Age and Medication used.

Participant	001	002	003	004	005	006	007	008	009	010	011	012	013	014	015	016	017	018	019	020	021	022
number																						
Current Age	53	44	47	50	47	52	43	53	46	43	41	47	39	43	48	55	39	46	56	43	51	41
Age at diagnosis	40	28	42	35	39	40	28	44	40	23	35	45	30	38	44	50	32	31	43	35	36	29
Age treatment started	41	41	42	36	42	42	29	44	41	29	39	45	34	40	45	51	34	35	44	38	40	36
							1															
Number of	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3
HAART tablets							(1)					(1)										
taken																						

Participant responses to Care provider seen.

Participant number	001	002	003	004	005	006	007	008	009	010	011	012	013	014	015	016	017	018	019	020	021	022
Family doctor	Y	Y	Y	Y	Y		Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Emergency department	-		Y		Y		Y			Y	Y		Y		Y			Y	Y			
Mental health counselor		Y	Y		Y		Y								Y		Y	Y	Y			Y
Dietician					Y	Y			Y	Y	Y	Y								Y		
Social worker	Y	Y		Y	Y		Y	Y	Y	Y		Y	Y	Y		Y	Y		Y	Y	Y	Y
Nurse	Y			Y	Y	Y		Y	Y	Y	Y			Y			Y			Y	Y	

Participant responses to Education and Status levels.

	Participant number	001	002	003	004	005	006	007	008	009	010	011	012	013	014	015	016	017	018	019	020	021	022
Marital	Single	Y			Y		Y	Y								Y	Y					Y	
status	Married		Y							Y													
	Co-habiting					Y						Y	Y								Y		
	Widowed				1			-						Y									
	Separated			Y	1				Y		Y				Y			Y	Y	Y			Y
Housing	BC housing	Y	Y		Y			Y	Y			Y	Y	Y		Y		Y	Y		Y	Y	Y
	Temp hotel			Y		1	Y			Y					Y		Y			Y			
	Own house					Y																	1
	Other			 							Y							<u> </u>					
Job status	Part time									-			Y									Y	1
	Unemployed		<u> </u>		1					-						Y	Y		Y				Y
	Employed seasonally	Y			Y			Y		Y			-							1	Y		
	On disability allowance		Y	Y		Y	Y		Y		Y	Y		Y	Y			Y		Y			
Education level	Elementary school		Y																				
	Some high school	Y		Y	Y		Y			Y		Y	Y	Y	Y	Y	Y	Y	Y	Y			Y
	High school					Y		Y	Y		Y										Y	Y	

Procedure and Ethical Considerations

This study involved engaging with an extremely vulnerable and marginalized part of the population on highly sensitive issues about themselves. Therefore, I took care to ensure that the interviews were conducted in a manner that did not harm the participants either physically or psychologically. Gaining entry to the study site was a process of tact, respect and understanding of the community. A clear understanding of the cultural, political and social protocol and the structure of the community in which the study was to be undertaken was essential. It was paramount to acknowledge that I was entering Aboriginal peoples' daily lives and as such I needed to be respectful of everyone's time and space.

Step 2 - Silence Before entering a Dialogue

In line with step 2 of The Vancouver School of Doing Phenomenology, before entering a dialogue there is reflective silence. This silence, being a process, meant it had to be reentered repeatedly as the study proceeded (Halldorsdottir, 2000). Firstly, in order to understand the phenomenon at hand, I had to go through a reflective silence. I engaged with the literature relevant to the study, reading as much as possible about HIV/AIDS and adherence to HAART in order to avoid narrowing my field of vision as well as not to miss any potentially crucial aspects. I also made a determined effort to undo the effect of habitual patterns of thought and, "return[ed] to the pristine innocence of first seeing" as described by Spielberg (1984, p. 680). It is important to note however that, being human, I may not have completely freed myself of my theoretical and epistemological commitments. Throughout the study, I kept a reflective journal where I wrote down my thoughts about each stage of the study and my reflections on my pre-conceptions about the phenomenon. I wrote about my own experience of seeing a lot of my relatives and friends struggle with and succumb to HIV/AIDS, and about working with those affected with the disease in Africa. After each interview I wrote about my impressions and the thoughts that went through my mind before, during, and after the interview process reflecting on my own experience. This process allowed me to proceed with the study being fully aware of, and setting aside, any preconceptions in order to hear the participants' story. Keeping a reflective journal helped me to identify and to work through the implications of my chosen framework. I used my research journal in a critically reflective way to consider who would benefit from the approach I took to my study. In some instances critical self-reflection prompted me to change the approach to interviewing. For example, after my first two interviews it became apparent to me that it was more important to keep track of and to address all questions listed in the interview guide whilst allowing the dialogue to develop naturally, and to enable myself to manage the interview while still respecting the principle of dialogue partner as expert.

I met with the Vancouver Native Health Society personnel at the VNHS clinic in Vancouver to discuss logistics pertaining to the study. Ethics approval was obtained from the Research Ethics Board at the University of Northern British Columbia (Appendix A). A letter of support (Appendix B) indicating permission to conduct this study was also obtained from the VNHS Research Advisory Committee. The study, its aims and methodology was explained and ownership of the research report ascertained. Most importantly, how the information will be used in the future was explained.

Preparation for the interviews was done following the principles laid out by McNamara (2009). These included: choosing a setting with little distraction; explaining the purpose of the interview; addressing terms of confidentiality; explaining the format of the interview; indicating how long the interview usually takes; telling participants how to get in touch with me later if they wanted to; asking participants if they had any questions before starting the interview; and making sure my recording instruments were functional so as not to count on

my memory to recall their answers (McNamara, 2009; Turner, 2010). Also, in line with Creswell's suggestion, I made all efforts to interview participants in a comfortable environment to minimize their chance of feeling restricted or uncomfortable to share information or "their story" openly and honestly (Creswell, 2007, p. 133). Another important element to the interview preparation was that an informal pilot test was conducted in Prince George with friends, two of whom had an Aboriginal background. The pilot test assisted me in determining if there were flaws, limitations, or other weaknesses within the interview design and questions and allowed me to make necessary revisions prior to the actual study (Kvale, 2007).

I informed all possible participants verbally about the study during meetings and events at the VNHS clinic and I told them that if interested in taking part they could meet with me at a time of their convenience. Letters explaining the nature of the study were handed out to all willing participants (Appendix C). Appropriate arrangements (time and place) were made for the interviews to be conducted. Interviews dates were set up with these participants in a back and forth collaboration with me so that the times would be convenient for them. Sometimes I had to change the dates or times at participant's requests, wait for the participants to have a break in their volunteer work, or wait for participants to have their lunches before proceeding with the interviews. Before the interviews and focus group, the study was explained to the participants (taking care not to influence participant's responses) and the necessary consent obtained (Appendices D and J).

The study was done over a period of five months. Firstly, 10 one-to-one in-depth interviews were conducted by using identical questions, but the questions were worded so that responses were open-ended allowing for information to be obtained without limiting the sequence and flow of the discussion (Appendix E and F). This open-endedness allowed the

participants to contribute as much detailed information as they desired, allowing them to fully express their viewpoints and experiences (Turner, 2010). This questioning process was also flexible in that I was able to probe, as a means of follow-up, for greater detail and depth, and to clarify different attitudes, perspectives and beliefs regarding adherence to HAART that otherwise might not have been revealed in a group situation (Gall, Gall, & Borg, 2003; Mack et al., 2005). I encouraged participants to elaborate on their answers with the aim of learning all they can share about the research topic. I did this without expressing approval, disapproval, judgment, or bias; keeping track of the questions yet letting the conversation to develop naturally. I also observed non-verbal behaviour and contextual aspects of the interview noting if the participant seemed distracted, became emotional over a particular question, or seemed reluctant to discuss a subject area. These social cues were added to the verbal answer of the dialogue partner on a question (Opdenakker, 2006).

Secondly, one focus group discussion, as described by Krueger and Casey (2000) and Mack and colleagues (2005), was conducted, with 14 participants, about issues pertaining to the factors determining adherence to HAART; and, to get insights, opinions, attitudes, and preferences from participants. It should be noted that only one focus group was conducted, instead of the two that were originally planned, because data saturation was achieved and there was no need to do a second one. A focus group is a technique involving the use of indepth group interviews in which participants are selected because they are a purposive sampling of a specific population, this group being focused on a given topic (Richardson & Rabiee, 2001; Thomas et al. 1995). The focus group provided information about a range of ideas and feelings, as well as illuminating the differences in perspective that individuals have about adherence to HAART. Furthermore, the focus group generated a lot of data in a relatively short time (Krueger & Casey, 2000). Since I was exploring very sensitive and personal issues, the inclusion of many participants that interact on a more or less daily basis at the VNHS clinic proved advantageous as there was already an extent of trust amongst the members of the group, which encouraged the expression of views. This factor was particularly important because very little information is available on the topic under study and the data from exploratory focus-group interviews may be used to formulate and design a large-scale study, as well as inform policy decisions (Krueger & Casey, 2000). The interviews and focus group were conducted at the VNHS clinic in an office designated for this purpose. On average, each interview took 30 to 45 minutes while the focus group took 1 hour 50 minutes. Each participant was presented with an informed consent form prior to individual interview and/or focus group discussion and told that by signing it they were giving consent to voluntarily participate in the study. At the end of each interview, and the focus group, and in situations where participants signed-up but did not attend, participants were reimbursed with \$20 in appreciation for their time.

Each participant of the in-depth interviews and /or focus group discussion was informed that their information and identity will be kept strictly confidential. Maintaining confidentiality required special precautions and emphasis in the focus group. For this reason, I avoided using participants' names during the focus group. Also, I asked each dialogue partner and focus group participant to fill in a demographic form (appendix H) with information regarding their identity, marital status, start of therapy, service provider utilization, location, education, and employment status to inform the results of this study. A system of name substitution (e.g., assigning numbers to participants) was implemented before the session began. Although I assured participants that everything they shared in the focus group would be treated as confidential, I could not promise that other members of the focus group would do the same. Emphasis was therefore made both at the beginning and end of the session that participants should respect each other's privacy and anonymity. Once outside the focus group setting, it was emphasized that they should neither reveal the identities of other participants nor indicate who made specific comments during the discussion.

In addition, permission to audio-tape the interviews and focus group was gained beforehand. Audio-tapes were transcribed verbatim, identified only by number, and securely locked in a filing cabinet. The transcripts were also anonymized. Transcription was done by me and a professional transcriptionist (after signing a transcribing confidentiality agreement) (Appendix I). Once a transcription was completed, I met with each participant back at the VNHS clinic, who then confirmed the data and the option was given to add any further reflections or withdraw some information.

Data Collection

Step 3 - Participating in a Dialogue.

In line with step 3 of the Vancouver School, I made sure to exercise complete concentration on the phenomenon under study, and paid attention to the dialogue partners, taking care not to lose awareness of context and self as a researcher. Also, because the Vancouver School is based on the will to understand, an initial distance and difference between persons in a dialogue was acknowledged, allowing the participant to tell their story, while my role was to listen and understand (Halldorsdottir, 2000). Each participant was seen as an expert and the whole data collection process as an inter-subjective interaction that brought out meaning (Halldorsdottir, 2000). I however, had to make conscious attempts to lay aside preconceptions about the phenomenon under study by keeping the reflexive journal.

Participants were asked to describe themselves and their experience as fully as possible, and to reflect upon their experiences. They were encouraged to feel free to speak and listen; to feel listened to and heard; to feel understood; and were hence empowered by the dialogue. During the study dialogue partners were asked questions that were in direct response to their last descriptions. I did this in order to arrive at a deeper level of understanding, to reflect and to validate (Halldorsdottir, 2000). It is through this inter-subjective interaction that the participants' essential description of their lived experience evolved.

Interview implementation.

Data were collected using open-ended questions. All the interviews were audio-recorded. Interview times ranged between 30 to 45 minutes. The focus group took 1 hour 50 minutes. Audio recording interview data was important for a number of reasons relating to both data management and analysis. Audio recordings helped me fill in blank spaces in my notes and in checking the relationship between the notes and the actual responses (Fasick, 2001). This potentially reduced bias and allowed me to reflect on the conversation to ensure that I adequately represented the meanings conveyed by participants. The presence of these audio recordings will also allow independent persons to certify that interviews were actually conducted and that the data reported are a true and accurate representation of the data obtained through the interview process (Halcomb & Davidson, 2006). In addition, in cases where there is ambiguity of meaning or inconsistencies, reviewers can refer to the audio recording to clarify the intended meaning from the original source (Fasick, 2001). Referencing back to the original recordings also provided me with examples to illustrate the study findings in the context of my written report (Fasick, 2001). When both are done together, as in this study, they complement each other. Taking notes during the interview is important for the interviewer, even if the interview is tape recorded: (1) to check if all the questions have been answered, (2) in case of malfunctioning of the tape recorder, and (3) in case of "malfunctioning of the interviewer" (Opdenakker, 2006). By both recording and

taking notes, I therefore captured the social process and context in its entirety and thus collected a more accurate and detailed account of what was said. There were other issues that were taken into consideration as the focus group progressed. These were the appearance of one being a dominant talker, extremely shy, disruptive, and/ or disrespectful of other participants. In line with recommendations by McNamara (2009), to avoid any of these issues occurring, I made sure, in a polite manner, to set ground rules upfront. I informed participants that all views were welcome, to treat each other with respect, to ask one question at a time or one person to talk at a time, and so forth. When appropriate, I reaffirmed by thanking the participant for sharing, for example, but then redirected the course of the group or provided transition between questions. I also attempted to remain as neutral as possible, not showing strong emotional reactions to their responses and only encouraged responses with occasional nods of the head. I was also careful about my appearance when note taking (e.g., not jumping to take a note as this may appear as if I were surprised or very pleased about an answer, thus influencing answers to future questions) (McNamara, 2009; Turner, 2010).

The questions, and the approach to interviewing, were modified to pursue emergent concepts as data collection and analysis progressed. Behavioural factors and socio-economic status were asked about to help in eliciting why one may/ may not adhere to HAART. Characteristics of Aboriginal men with HIV who feel they are successfully and consistently able to seek/ receive treatment as well as their unsuccessful counterparts were sought. This enabled me to get a better picture of how strongly personality factors influence health behavioural decision making. It should however be noted here that there is no gold standard for the assessment of adherence (O'Brien et al., 2003), but there are many validated tools and strategies from which to choose. Patient self-report of adherence predictably overestimates adherence by as much as 20% (Arnsten et al., 2001). However, this measure is still associated

with viral load responses (DHHS, 2009). Thus, a patient's report of suboptimal adherence is a strong indicator of non-adherence and therefore, even though not measuring adherence as such in this study, a participant's self-report is what I considered as truth of one's adherence practice. Other important factors such as geographic location, proximity to treatment, transportation/ access, efficacy beliefs, modeling of help-seeking behaviour (for disease treatment), were also considered.

Also, true to an assertion by Creswell (2007), participants in some of the interviews in this study did not necessarily answer the question being asked and, in fact, some answered a question that was asked in another question later in the interview. Being aware beforehand that this could happen, I therefore made sure I was always prepared with follow-up questions or prompts in order to ensure that I obtained optimal responses from participants. In some of the interviews, and in the focus group, some participants veered off topic with certain questions either because they did not wish to answer the question(s) directly or they misunderstood the question(s) being asked altogether. In such situations, I either used effective follow-up prompts to further understanding or reconstructed questions so that they were clearly understood (Creswell, 2007). In the end, I obtained the information I needed from the interviews and focus group.

Data Analysis

All the audiotapes were first transcribed verbatim. *Verbatim transcription* refers to the word-for-word reproduction of verbal data, where the written words are an exact replication of the audio recorded words (Poland, 1995). However, the combination of verbatim transcription and notation of participants' nonverbal behaviour adds to the reliability, validity, and veracity of the data collected (MacLean et al., 2004). Also, since this study is underpinned by phenomenology, this verbatim record of the interview was clearly beneficial

in facilitating data analysis by bringing me closer to the data. All the transcripts were entered into the QSR NVivo data management program and data coding was undertaken. The manual method of using different colour markers was also used alongside.

The analysis for this study was done using the qualitative technique of thematic analysis, which incorporates the inductive bottom up way approach (Braun & Clarke, 2006). This is incorporated in (although not explicitly stated) the Vancouver School of Doing Phenomenology. Thematic analysis is a search for themes that emerge as being important to the description of the phenomenon (Daly, Kellehear, & Gliksman, 1997; Fereday & Muir-Cochrane, 2006). It is a form of pattern recognition within the data, where emerging themes become the categories for analysis. This inductive approach meant that the themes identified are strongly linked to the data themselves (Patton, 1990) and not driven by my analytic preconceptions or theoretical interest in the topic. The analytic process therefore involved moving from description, where I organized data to show patterns, to interpretation, where the significance of the patterns and their meanings and implications were brought out (Patton, 1990).

Step 4 - Sharpened Awareness of Words

In line with the Vancouver School, data collection and data analysis were run concurrently. Step 4 involved being immersed in the data to the extent that I was familiar with the depth and breadth of the content in order to get a sense of the lived experience as a whole. I searched for meanings and patterns through "careful reading and re-reading of the transcripts" (Rice & Ezzy, 1999, p. 258). The first time I read each transcript, I read with an open mind, listening attentively trying to feel the participants' descriptions and making sense out of them (Colaizzi, 1978).

Through having transcribed some of the interviews I developed a far more thorough

understanding of the data as it informed the early stages of analysis (Lapadat & Lindsay, 1999). For the interviews that were transcribed for me, I spent more time familiarising myself with the data. However, being aware of possibility for errors in verbatim transcription (MacLean et al., 2004), cross-checking of data was undertaken from the original digital recordings (Fasick, 2001). I also started taking notes and marking ideas for coding that I would go back to in subsequent stages. I also reflected on some possible initial analytic interests and thoughts.

Step 5 - Beginning consideration of Essences: Coding

According to Halldorsdottir (1990), coding involves firstly identifying the significant or key statements that have an important bearing on the phenomenon under study. Secondly, it involves identification of themes of these key statements, coding the themes and writing down the names on the transcript and/ or in a computer program. In so doing, meanings are formulated (Colaizzi, 1978). Codes identify a feature of the data that appears interesting, and refer to "the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon" (Boyatzis, 1998, p. 63). Coded data differ from the units of analysis (themes), which are (often) broader. In terms of themes, arguments about the phenomenon under study are made and the interpretative analysis of the data occurs (Boyatzis, 1998).

After I had read and familiarized myself with the data, and generated an initial list of ideas about what was interesting in the data, step 5 began. To produce initial codes from the data, I coded both manually and through NVivo. As codes were developed, they were applied and compared to newly collected data and modified as necessary. I worked systematically through the entire data set, developing data-driven codes, giving full and equal attention to each data item, and identifying interesting aspects in the data items that later formed the basis of repeated patterns (themes) across the data set. I printed transcripts and manually coded data by writing notes on the texts and using highlighters of different colours to indicate potential patterns. I then matched the identified codes with data extracts that demonstrated that code. I ensured that I coded all actual data extracts, and then collated data together within each code. I did this by copying extracts of printed data from individual transcripts, and collated each code together in separate files. When using NVivo, I coded by tagging and naming selections of text within each data item.

After I had initially coded and collated all the data, I had a long list of the different codes identified across the data set. I proceeded to sorting the different codes into potential themes, and collating all the relevant coded data extracts within the identified themes. I analysed my codes and considered how different codes combined to form an overarching theme. I used visual representations to help sort the different codes into themes. I wrote the names of each and every code (with a brief description) on separate pieces of paper and organized them into theme piles. Some initial codes formed main themes, whereas others formed sub-themes, and others were discarded. I also had a set of codes that did not seem to belong anywhere, these I placed in the 'miscellaneous' file. By the end of this stage I had a sense of the significance of individual themes.

Step 6 – Constructing the Essential structure of the Phenomenon for Each Case

In line with step 6 of the Vancouver School, I took all the different themes constructed in each case and put them together thereby constructing the essential structure of the phenomenon for each dialogue partner – each case (Halldorsdottir, 1990). I took time to create a conceptual picture of the phenomenon according to how each participant had experienced it (i.e., true to the lived experience of that individual). I processed the ideas and organized them to reach conclusions, using my understanding of each situation and turning

attention back towards my own thoughts. Again and again I had to be attentive, going through the process of silence, reflection, interpretation, construction and verification. Through this process, therefore, the meaning of each experience came out.

Step 7 – Verifying the Single Case construction with Each Dialogue Partner

According to Morse and colleagues (2002), the process of *verification* enables one to be certain of data accuracy by checking, confirming, and making sure (Morse et al., 2002). In step 7 of the Vancouver School method, I repeatedly went back to the VNHS clinic to verify each case construction with the relevant participant in order to make sure my preconceptions, although ardently laid aside, did not bias the data, that nothing was left out, and that the construction was a reflection of the participant's own story. This was another opportunity for me to ask each participant if they had anything else to add to the information they had provided. According to Guba and Lincoln (1989), this procedure, called "member checks", is regarded as "the single most critical technique for establishing credibility" (Guba and Lincoln, 1989, p. 239). The verification process was helped in part by the fact that most participants either attend the men's group at VNHS clinic once a week (every thursday) or volunteer there making it easy for me to locate them for verification. However, this was a daunting task in that it took a long time for me to find three of the participants as they did not use the VNHS services much.

Step 8 - Metasynthesis: constructing the Essential structure of the Phenomenon

The essential structure (or analytic framework) is a description, an interpretation, an explication of the phenomenon (Halldorsdottir, 1990). In order to construct the essential structure of the phenomenon, I read and re-read the transcripts, comparing the different dialogues in order to find the similarities, as well as differences, in the cases so as to bring out the daily lived experience of HIV/AIDS into the open so that those who are unfamiliar

with it can appreciate and understand it. Again, this step involved processing the data and organizing it to reach conclusions, using my understanding of each situation and turning attention back towards my own thoughts, going through the process of silence, reflection, interpretation, construction and verification.

Step 9 - Comparing the Essential structure with the Data

In order to do justice to all the data (Spielberg, 1984), I investigated the data equally and considered all potential outcomes. Having identified the essential structure of the phenomenon, I referred clusters of themes back to the original protocols, comparing the transcripts in order to see whether they fit the actual data, hence validating them (Braun & Clarke, 2006; Colaizzi, 1978).

The aim here, according to Patton (1990), is that internal homogeneity and external heterogeneity are achieved (i.e., data within themes should cohere together meaningfully, while there should be clear and identifiable distinctions between themes) (Patton, 1990). I therefore reviewed all the dialogues firstly at the level of the coded data extracts. I re-read all the collated extracts for each theme, considering whether they appeared to form a coherent pattern in relation to the data set. I also looked for any additional data within themes to make sure nothing had been missed in earlier coding. All themes were therefore organized into a coherent and internally consistent account, with accompanying narrative. For each individual theme, I conducted and wrote a detailed analysis. I also identified the story that each theme told, and considered how it fit into the broader overall story about adherence to HIV/AIDS.

In doing this step, some themes ended up collapsed into each other. Still others were broken down into separate themes. By the end of this step, I could clearly define what my themes were and what they were not.

Step 10 - Identify the Over-riding Theme(s) which describe(s) the Phenomenon

According to the Vancouver School, the route of silence, reflection, selection, identification, interpretation, construction, and verification is again used repeatedly, comparing the essential structure with the raw data in order to identify the over-arching or core themes that capture the phenomenon (Halldorsdottir, 2000). In step 10 therefore, building upon already identified themes, I read and re-read the data, comparing the essential structure with the raw data. I played around with the themes, clustering them, and assigning phrases to describe the meaning that under-pinned the core themes. The final analytic structure of the phenomenon was therefore a construction of meaning.

Step 11 - Verifying the Essential structure of the Phenomenon with Dialogue Partners

After one of the men's meetings, I introduced my final analytic framework to some of the participants who had taken part in my study in order to see whether they recognized in it the analytic description of their own experiences and also to be certain that the final meaning was true to the participants' stories. Dialogue partners for this final validation step were chosen, preferably those who had a broad picture of the phenomenon in their mind and a deep understanding. Also, these dialogue partners were given another opportunity to validate their original interview transcripts, their initial case structures, and the themes that arose from the data.

Step 12 - Writing up the Findings

I began this step involving the final analysis and write-up of the report, when I had a set of fully worked-out themes. I quoted the dialogue partner's own words in my writing as much as possible in order to furnish the phenomenon and thus tell their stories. I wrote up the findings constructing a multi-voiced text where everyone involved had a voice. In line with Braun and Clarke (2006), I embedded extracts within the analysis that illustrate the story I was telling about the data, and made an argument in relation to my research question (Braun & Clarke, 2006). I took care to make sure my analysis provided a concise, coherent, logical, non-repetitive and full account of the story the data tells, within and across themes.

Validity or Trustworthiness of Research

According to Collingridge and Gantt (2008), validity refers to the extent to which research measures what it purports to measure. Maintaining the validity of qualitative research is important for all methodologies if they are to accurately reflect and answer the researched issue. In the method of phenomenology, validity or trustworthiness is cultivated in the participant's stories as they are self-interpretive. However, since there is always the likelihood that a question or answer will be misunderstood or misinterpreted, steps were taken in the study in order to achieve validity or trustworthiness. Expert opinions were sought from both my supervisors and colleagues, and literature searches also done, to establish content validity (i.e., whether the questions provide adequate coverage of a topic).

In line with suggestions by Wolcott (1990), I made sure to listen well, record all information, initiate writing early, include all relevant data in the final report, reveal feelings to the matter at hand (if relevant), and to seek feedback from participants (by showing each individual participant his transcript) to ensure that information was reported accurately and completely.

In the Vancouver School, the researcher is seen as the research instrument, therefore, validity is also seen as hinging to a great extent on the skill, competence, and rigor of the researcher. This view is echoed by Patton (2002) who claims that the validity of qualitative data "depends to a great extent on the methodological skill, sensitivity, and integrity of the researcher" (Patton, 2002, p. 5). Guba and Lincoln (1981) go further by calling for the investigator to have a holistic view and be both responsive and able to adapt to changing

circumstances that determine the reliability and validity of an evolving study. Therefore, at all stages of the research process I remained open, using sensitivity and creativity, and considered all ideas, even those poorly supported, in order to build each participant's true story. I made sure I read my literature extensively prior to and during the study. At the same time I listened closely to data, making sure to set aside previously held assumptions. In line with the Vancouver School, validation therefore became investigation, continually checking, questioning, and theoretically interpreting the findings (Halldorsdottir, 2000).

In line with recommendations by Lincoln and Guba (1985), to attain trustworthiness I looked at four aspects: credibility, transferability, dependability, and confirmability. Within these were specific methodological strategies for demonstrating qualitative rigor that I applied, such as an audit trail (keeping track of interviews conducted and specific times and dates, and analytic decision-making points made), member checks, and prolonged engagement (Lincoln & Guba, 1985; Morse et al., 2002).

The credibility criteria involved establishing that the results of the study are believable from the perspective of the dialogue partners. Since from this perspective, the purpose of the study was to describe or understand the phenomena of adherence to HAART from the participant's eyes, the participants are the only ones who could legitimately judge the credibility of the results. I therefore worked closely with my supervisor to ensure that the reconstruction and representation of the respondents' views on adherence to HAART were thematically coded and depicted accurately. In addition, I crosschecked my overall understanding of what was reported with some of the dialogue partners. Firstly, I took transcriptions to participants prior to analyses and interpretations of results. Secondly, I took analyses and interpretations of data to participants for validation of (or support of) my conclusions.

A combination of different methods (i.e., focus group discussion and one-to-one interviews) as a form of triangulation, was used to search for consistency between data and to give a more rounded picture of the study (Farmer et al., 2006). This triangulation helped to enhance the validity of the research by increasing the likelihood that the findings and interpretations will be found credible and dependable (Lincoln & Guba, 1985). The underlying assumption was that "the validity of research results is enhanced if the different methodological approaches produce convergent findings about the same empirical domain" (Erzerberger & Prein, 1997, p. 144). Through methods of triangulation, I first related information obtained from the focus group and interviews to each other, and then documented each comparative step taken in the triangulation process to ensure transparency and replicability. A further step to the triangulation process that was helpful was sharing the triangulated results with the dialogue partners, discussion of any issues of significant disagreement and incorporation of dialogue partner changes into the data interpretation. I also conducted peer debriefing with one researcher familiar with the phenomena of adherence to HAART who provided critical feedback on descriptions, analyses, and interpretations of the study's results.

Transferability refers to "the degree to which the results of qualitative research can be generalized or transferred to other contexts or settings" (Trochim, 2006, \P 4). The purpose of this study, however, was not to generalize the findings to a larger population, but to elicit the determinants of adherence to HAART in Aboriginal men in the DTES of Vancouver, and to provide recommendations for action that are culturally sensitive to the researched community. In case other researchers want to transfer the results, I made sure I enhanced transferability by doing a thorough job of describing the research context, assumptions central to the study, establishing the degree of similarity in the dialogue partner's views with

other previous research data on the same subject, giving a thick, detailed report with sufficient quotes so that researchers, and other readers alike, can make interpretations and conclusions and determine the degree of transferability to their own situations.

The aspect of dependability concerns the stability of data over time as it emphasizes the need for the researcher to account for the ever-changing context within which research occurs (Lincoln & Guba, 1985). To this effect, I performed an extensive literature review and described the changes that occurred with respect to adherence to HAART over time and how these changes affected the way I approached the study. Study findings, both similar and dissimilar, have been provided in this report and can be traced for verification.

Confirmability refers to the degree to which the results could be confirmed or corroborated by others. As explained earlier, I documented the procedures for checking and rechecking the data throughout the study in order to enhance confirmability.

It should be noted that, while strategies of trustworthiness are useful in attempting to evaluate rigor, by themselves they are not sufficient. Therefore, verification strategies suggested by Morse and colleagues (2002) were also followed during the conduct of the study. I ensured methodological coherence and sampling sufficiency, and moved back and forth between design and implementation to ensure congruence among question formulation, literature, recruitment, data collection methods, and analysis (Morse et al., 2002). Some questions had to be modified during the study, and the sample expanded, from the original plan, to reach saturation. Data were systematically checked, whilst maintaining focus throughout the study, and interpretation was confirmed constantly. I made sure in the study, however, that the sample was appropriate, consisting of participants who best represented or had knowledge of adherence to HAART thus ensuring efficient and effective saturation, with optimal quality data. Sufficient data to account for all aspects of the phenomenon were therefore obtained. According to Morse and colleagues (2002), "saturating data ensures replication in categories; replication verifies, and ensures comprehension and completeness" (Morse et al., 2002, p. 18). As mentioned before, I also collected data and analyzed it forming an interaction between what was known and what evolved from the study. Further, I thought theoretically, reconfirming ideas emerging from data in new data; this gave rise to new ideas that, in turn, were verified in data already collected. The process required moving forward without making cognitive leaps, constantly checking and rechecking, and building a solid foundation. Lastly, a consistent and logical theory was developed as an outcome of the study process, and informed by the data collected. By the end of the study, all the verification strategies contributed to and built trustworthiness, thus ensuring rigor.

Assumptions

It is important to identify assumptions I had in mind prior to conducting this study. To begin with, I made assumptions about the nature of reality (ontology) and about what is (or should be) regarded as acceptable knowledge (epistemology). I came into the study accepting the idea of multiple realities instead of a single reality (Cresswell, 2007), that reality is subjective, as seen by "participants' eyes" in the study. Therefore, I took what the respondents said in answer to research questions as truth. I then used quotes and themes in words of participants and provided evidence of different perspectives. Since I was undertaking qualitative research, I thought that I could learn the most by seeing/ investigating human behaviours in their total, participating in a research, and/or by experiencing the situation firsthand (Bryman, 2004), and by providing a detailed report of the participants' understandings of the situation (Firestone, 1987). Reality was indeed experienced, and thus constructed, by the participants in this study and, in line with Smith and Heshusius (1986), understanding this guided the interpretation of findings (Smith & Heshusius, 1986).

I also assumed that the questions used would have content validity and fully explore the participant(s) views on what the determinants are and how they affect adherence to HAART. I also assumed that participants were less likely to trust me, viewing me as an outsider. However, it turned out untrue. The seven months I had spent volunteering at the VNHS and participating in men's meetings, my family experiences of HIV/ AIDS, as well as my history of having worked with those suffering from the disease in Africa, had helped build trust between me and the participants. Another assumption I made was that historic trauma would be a central point of discussion throughout the interviews. I based the assumption on the amount of literature I had come across documenting the connection between historic trauma and health in Aboriginal peoples. The study, however, showed that not all participants believed historic trauma had an effect on their adherence to HAART.

With the knowledge of my assumptions and biases, I made a conscious effort to bracket out pre-knowledge and preconceptions during the study and to remain open to participants' stories, and continually wrote in my reflexive journal.

Summary

In this chapter the methodology used in the collection and analysis of data was discussed with special reference to the research paradigm, setting, sample, procedure and ethical considerations, data collection, data analysis, validity of the research, and assumptions.

The next chapter presents the findings of the study.

Chapter Four

Results

Introduction

This chapter outlines the findings of the study. Quotes from participants are provided to illustrate their stories and to build the essential structure of the phenomenon. Participants are referred to by number only.

The essence of the phenomenon was characterized by five over-riding themes: (1) patient factors, (2) inter-personal factors, (3) support structures, (4) history of trauma/ residential school attendance, and (5) medication-related factors. Furthermore, secondary themes are organised under the five main themes. Under patient factors the subthemes are: psychological factors (depression, alcohol and drug addiction, fear, not caring, procrastination or being busy and, traditional beliefs), socioeconomic factors (employment status/ volunteering and housing), and other (knowledge, memory loss). Under interpersonal factors the subthemes are: stigma and discrimination (in the health care facility, on the street, or on the reserve), and patient-care provider relationship. Under support structures the subthemes are: food provision, staff and friend's support, counselling, medication pick-up routine and outreach, methadone maintenance treatment, availability of funding and services, and Aboriginalcentered services and practices. Under history of trauma/ residential school attendance the subthemes are: drug abuse, low self-esteem, self-blame, insecurity, fear, resentment, and other effects. Finally, under medication-related factors the subthemes are: complexity of treatment and side effects. The essential structure of the phenomenon of the determinants of adherence to HAART is shown in a schematic way in Table 5.

Factors that Influence Adherence to HAART

Themes	Subthemes
1) Patient factors	Psychological factors
	Socioeconomic factors
	Other factors
2) Inter-personal factors	Stigma and Discrimination
	Patient-Care provider relationship
3) Support structures	Availability of and Access to food
	Staff and friends' support
	Counseling
	Medication pick-up routine and outreach
	Methadone Maintenance Treatment
	Availability of funding and services/programs
	Aboriginal-centered services and practices
4) History of trauma/	Drug use
residential school	Low self-esteem, self-blame, insecurity, fear, resentment
	Other effects
5) Medication-related	Complexity of treatment
factors	Side effects

The results for the thematic analysis for individual interviews are summarized in table 6.

Table 6

Summary thematic c	analysis for the	ten dialogue partners
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Participant	Theme 1	Theme 2	Theme 3	Theme 4	Theme 5
number	Patient	Inter-	Support	History of	Medication-
		1			1,1
	factors	personal	structures	trauma/	related
		factors		residential	factors
				school	
001		✓ ✓		✓ ✓	
002	✓	✓	✓	 ✓ 	
002					
003	, v			· ·	¥
004	✓	✓	✓		✓
005	✓		✓		
006					1
000					
007	✓		✓	✓	
008	✓	√	✓	~	
009	✓ √		✓ →	✓	
009					
010	✓		~		
			10		
Total	10	4	10	6	3

The results for the thematic analysis for the focus group are summarized in table 7.

Table 7

Summary thematic analysis for the 14 focus group participants

Donticipant	Thoma 1	Thoma 2	Thoma 7	Thoma 1	Thoma 5
Participant	I neme I	1 fieme 2	Theme 5	Theme 4	I nemie 5
number	Patient	Inter-personal	Support	History of	Medication-
	factors	factors	structures	trauma/	related factors
				residential	
				school	
011	v	\checkmark			
012	1	~		1	1
013	~	~	\checkmark		
014		~		<u>,</u>	
015		~	\checkmark		
016	1		\checkmark	\checkmark	4
017	1	\checkmark			
018		\checkmark		~	
019		\checkmark		\checkmark	
020	\checkmark	1			
021			\checkmark		~
022	✓		\checkmark		\checkmark
023	✓	✓	 ✓ 		\checkmark
024	\checkmark	✓	\checkmark	\checkmark	
Total	9	11	7	5	5

Patient Factors

Psychological Factors

Depression.

Depression has been shown to be closely associated with non-adherence to therapy, which in turn, is associated with both disease progression and survival (Simpson et al., 2006). In this study, some of the dialogue partners indicated that depression is an important factor as far as adherence to HAART is concerned. They stated that during times of depression one is less likely to take his medication. It seemed that this was equally true of most of the focus group participants. However, only five participants were currently on antidepressant medication. The following quotes were some of their responses:

When I get into depression, I need supervision to make sure I take these pills, because when I fall into depression or uh, feeling of, "Poor me." I stop taking the meds, not because of any um, any conscious thoughts of committing suicide. It's about me just angry and not thinking. I get depressed then the anger comes out as a way of trying to control the depression and um, I forget meds (002).

When I first got diagnosed I found depression was the only factor that really prevented me from taking those pills. When I first started, I looked in my hand and I got pills - uh I was thinking to myself "I'm holding my life in my hands right now" and that really got me, so I still managed to take them but I did miss a few when I first started because of that reason (012).

Alcohol and drug addiction.

The use of illicit drugs and alcohol has been associated with poor adherence to HAART (Chandler, Lau, & Moore, 2006; Tyndall et al., 2001). Alcohol and illicit drug use came out as a major factor as it was voiced by 16 of the study participants. Some respondents indicated that they would forget to take their medication following a drug binge whilst others said that they would prioritise taking illicit drugs over their medication when both are available:

Um, some, like I say, um, sometimes I get into my addiction. I get into my addiction and I start using and then I forget to show up here, hey. And that, and then I forget my meds (003).

Before I uh, I was on drugs, I'd forget to take my meds. I missed my appointments because I couldn't do it. I was hooked on heroin all the time (004).

Oh, um, um, drug use, um, just forgetting. Um, thinking that I took them and I didn't and um, mostly just drugging. Like using drugs and going on a run and stuff that would, that was um, you know why I, I didn't take them (009).

My situation's like a lot of other people and it's up, if I'm on like a trip, like a drug binge, I'll put, I'll put the ARVs in the back burner, I won't, you know, it's not that important at that moment eh, and that moment you know, from my situation, whether I had a weekly supply, daily supply or monthly I wouldn't take them, it wouldn't matter for me, personally (017).

Yeah, they could be right in front of me whether I had to or what - for me personally, it wouldn't matter. The drugs would come first and the ARVs would come last (016).

But I think around here, that's probably 99.5 percent - the only reason that most people here might forget their medication, because they get sidetracked by drugs (012).

So the only time I miss is if I am on a binge. It's not that I don't want to take them, it's just that I forget and that's at night and not in the morning (020).

When I'm drinking (alcohol) I miss two days (007).

Well with drugs you, you get easily distracted (013).

One respondent went a bit further and explained that what may fuel high illicit drug use

may be that some view the practice as acceptable. He lamented:

I, I might be a little bit off the subject, but in HIV I think why it isn't, levelled out in Vancouver is because we've got an open drug scene from all the way from Cambie street right to, right to umm, right to all the way to Main street. I mean I could look down, right, pretty well acceptable in, and do it right on the main street and, and for the drug use and for the gay community it's more acceptable in west round down to Davie..., you know what I mean? It's still, it's more acceptable. There's a few ignorant people that might be uh aggressive towards but I think most are drug-- I think it's, it's more, it's more open I think and that's why it isn't, it isn't come down - the HIV rate - you know (021).

Fear of getting more sick or dying.

Respondents in this study indicated that the fear of getting more sick or dying remained

omnipresent in their lives, especially with adherence to HAART, with many being aware that

treatment would give them the opportunity to live a long and healthier life. Some respondents

commented:

I mean HIV, it kills. I know a lot of people are dying from it and I don't want to be known as (the one who) died from HIV. I don't want to be known as that. I want to live a long life even though I'm old, I'm an older guy (012).

I know, how, how fast I get sick and what it's like to feel that way because it's, it's nothing I wanna, it's nothing that I wanna go through again - that's why I'm taking my medication (022).

I don't wanna-- I got scared - so I didn't want to die. So I decided I'm going to go take these pills (006).

I don't wanna be sick and skinny and dying, you know what I mean? I wanna be uh, I wanna be healthy for, for, for my life (010).

Not caring, procrastination or being busy.

A few of the respondents indicated that lack of care or responsibility on their part

contributed to decreased adherence to HAART:

Just being irresponsible. Just not caring enough to, to open their fridge and take them out and, you know, and do it (010).

Procrastination has been found to contribute to poor adherence (Metsch, Pereyra, &

Brewer, 2001). A few participants alluded to their reduced adherence:

When I don't have a reason to get up in the morning, um that's when I start.."I'll take it later. I'll do this later. Later, later, later". Procrastinating and I never, nothing gets done (022).

According to Conway (2007), HIV/AIDS patients may also miss treatment due to being

busy. A few participants cited being busy as a reason for reduced adherence:

But still, then your, sometimes when I'm rushing and I just forget or and I just-- then I would, when I leave "oh man, I forgot to take my meds" because I'll do something, I'll take it later, I'll do this and that (008).

I was too busy [trying to go eat]. I got up late and I just didn't have time. When I finally got home I just forgot all about it. It wasn't on my mind anymore. If I don't do it in the morning, I forget about it (002).

My problem is I get sidetracked by the work I do and then I miss my meds (011).

One other response was unique, but encouraging in that the respondent seemed to have a

mindset which facilitated his adherence to HAART:

I think it's easy to take your meds if you really, you really want to. Like I didn't wanna take them. And then one day I decided it's time to take them and so when I knew that day was gonna come, it uh, I just knew I would wanna do it. Now that I'm on it I think it's very, very important and I think it's one of the more important things in my life to, to want it, to manage and to be uh, um, consistent every day (010).

Traditional beliefs.

Traditional beliefs of whether one has emotional and/or spiritual balance have been shown to affect one's ability to cope with HIV/AIDS and its treatment (McLeod, 2004; Montour, 2000). A few respondents believed that adherence to, and effectiveness of, HAART depended on what state their spirit was in to begin with:

I grew up knowing my cultural traditional practices and to me I find that uh, uh, uh if my spirit is low, I'll not take my medication, any kind of, any kind of medication or what's that, medicines, didn't work or they don't work as well. If you're, if you're okay with yourself, or if you're happy, your recovery is going to be just sky rocketing. Or if your spirit is low it takes a lot longer for medication to set in (017).

Socioeconomic Factors

Employment statu s.

Employment status is an important factor to consider when looking at adherence to HAART. A low income has been associated with weight loss (Voight, 1994) and indirectly associated with low adherence to HAART (Kleeberger et al, 2001). Some of the participants in this study expressed the view that, because of being unemployed, they have difficulty meeting their food needs and purchasing other daily necessities. The following quotes from the respondents highlight these challenges:

You know, yeah, money too, that's a, that's a major issue on my brain. All the time, constantly seeking money. I spend more time seeking money, trying to provide myself with cigarettes and just the basic needs that I, I really don't have time to take any medications (024).

Uh yeah I come volunteering once in a while. Good. I like it. It keeps me busy and it uh, I don't crave for drugs or anything like that, you know (004).

Housing.

According to Wolitski and colleagues (2007), adherence to HAART may depend on whether one is homeless or not. Furthermore, those who are homeless often have a distorted sleep pattern which may lead them to sleep through medication time (Laws et al., 2000; Reback, Larkins, & Shoptaw, 2003). Some may not even remember if and when they last took their HAART. One of the participants commented:

Yeah, when I was homeless before I used to have a hard time because you know sometimes I don't sleep, and then when you finally sleep you sleep for days and so, you know, that's another way how you miss meds too,...because you forget (012).

Other Factors

Knowledge of drug resistance or interactions.

Functional health literacy has been shown to be related to adherence (Van Servellen et al.,

2002). A good number of participants indicated that their knowledge of drug resistance and

drug interactions helps them take their medication regularly:

If you stop the meds, your body rejects the medication and after if you - the doctor says - if you quit taking them all the time, you can't just start up - your body wouldn't, wouldn't be, wouldn't fight it off and that's, there wouldn't be no help for you (001).

Yes, I've missed a few days here and there, yes. And they told me to be careful because my body can reject the um, the um, the medication (003).

Um, I keep it in my mind that if I keep missing that um, the meds, my body will get immune to it and it will start rejecting it and I don't want that, like (005).

Um, like when I found out I was on, on the, um, affected, I quit drinking so my medications would work because if you drink and you take pills, they won't work (009).

One respondent, however, said that it did not really bother him if he missed some of his

medication. He commented:

I made an exception, an exception to the rule - even if I miss them for a week or two weeks, that resistance doesn't bother my system. It does probably, you know, but when I go back and do a blood test my viral level is undetectable, my CD4 level is still up there, about 500. But most cases, I think the drug would not work, eh? Like, but it seems like it works for me, still, maybe because I've used it for eight years - there's so much in it, my blood stream, my tissue, my body (012).

Memory loss.

Memory loss in HIV/AIDS patients has been associated with low adherence to HAART

(Meyerhoff, 2001; Selnes, 2005). One respondent in the study cited memory loss as a

significant factor leading to low adherence to HAART:

Sometimes I forget if I take them or like, sometimes I have this memory loss. It was really bad and um I noticed I didn't have as much uh memory loss like before - like I'm trying to figure out why um, why I lose my memory now, forgetful now and then, you know (008).

Yeah, maybe two out of three days sometimes, you know, yeah. That's when I know I'm

getting really, getting sick, that's when my memory loss is kicking (in) (008).

Interpersonal Factors

Stigma and Discrimination

Stigma and discrimination not only determine whether people will step forward for care, treatment and support, when HIV-positive (CAAN, 2004), their presence has also been shown to lower adherence to HAART (Rintamaki et al, 2006). A few interview dialogue partners and many focus group participants in this study expressed their experience of stigma and discrimination and how these affected their adherence to HAART:

Stigma and discrimination in a health care facility.

Um, the problem is, is it's hard to get, because there's a stigma down here about you, anyone being an addict. That uh, they don't want, the doctors here don't want to create another addict, ...like we're talking about heroin, um, pain medication okay. It could be whatever going down the list right down to Aspirin, doctors are reluctant in the downtown east side to hand out this kind of medication. But the person's already a drug addict (002).

And uh it's combination because, because it's appearance, because he's native, and uh he actually went through it with the doctors years ago because he, they asked him "do you do drugs? Do you drink and do drugs?" and he said no so they asked him the question again like that's the wrong answer (017).

Stigma and discrimination on the street.

I think that, I think uh, well I know with myself in a real small, smaller community and it was known that I had HIV and that, I would start to be treated, you know, with disdain, that I know it would have a great effect on my ability, especially if I had to go in and get medication - pick it up daily - I wouldn't want to go in (019).

I don't fit in as a working person anymore because of stigma attached to HIV. I can't get a job anywhere. The minute I tell them I've got HIV, they're gonna put me out the door (012).

No it happens quite a bit. There's a lot of things out here to make a person angry. One of them is a lack of uh, uh recognition for me as a human being. Okay, that's one of the things that I sadly don't like at all. I hate it is that they just, I'm just a, a tool. I'm, I don't have any connection in the community really. I'm on the outside (002).

"Oh no, now I'll never be able to participate in the real world. I'll never be able to." Because at that time I got it, there was quite a stigma attached to it. You were either gay or you were a drug user and the minute you mention HIV and if you don't look like you were gay that meant you were a drug user. And nobody wanted you around to begin with, because that was stigmatized as well (023).

Stigma and discrimination on the reserve.

When I first got diagnosed with HIV and I went home to see my, my family and my friends - they found out what I had and I was totally ignored and they didn't want to have nothing to do with me, sit beside me, or even be close to me. And I had to teach my parents about HIV and they figured it was contagious, eh, they didn't want to be near me (017).

My partner went back home and his dad said uh, he went all the way and his dad goes, he goes all the dayand his dad says - he heard him asking-- has he given the dog AIDS and he's sitting on the toilet, well I have to clean the toilet seats with bleach. So we just left. Oh in a great city to see him, because people are ignorant (018).

Patient-Care provider relationship

The type of patient-care provider relationship affects adherence to HAART (Demmer,

2003; Schneider et al., 2004). Some of the participants in the study reported that their

relationship with their care providers was a factor determining adherence to HAART. The

following responses exemplify this:

'Cause it's a trust issue, it's not this. It's a trust issue. Doctors are asking you to come trust him to take care of your health. Um, but when you come in there and he refuses you certain medications, he's not got your best interest at heart (002).

At first the doctors uh, I'll say uh, they uh, they used me for who I was. Like, say I was a drug addict, they used that against me. They didn't give me the pills I needed and I know what worked for me. Sometimes I'd ask for it and I wouldn't get until I had to beg for it, you know. And I shouldn't have to do that. And now um, my doctor understands what kind of person I am (004).

You know what I think makes all the difference in the world in regards to health, especially for people in this area - is the caregivers - that if you go someplace for medical care and you're not treated with any kind of dignity or respect what are you going to feel like? I ain't going to go back to that place (014).

Uh, it's a, it's about a trust issue. It really is the whole trust between a doctor and a patient. The, and, and when you're a drug addict there is no trust, no one can trust you enough (024).

Support Structures

Availability of and Access to Food

Nutritional needs of people living with HIV/AIDS are increased because the body has to

fight the virus and opportunistic infections (UNICEF, 2010). One's access to food, as well as

adequate nutrition, has been cited by almost all participants in this study as an important

determinant of adherence to HAART. Participant responses are represented below:

I come next door for my meds, my meds. Every Saturday now, he gives umm Chinese food to coax me to come in and get my meds everyday otherwise I wouldn't take them. Buys me dinner on every Saturday so I can take them because I -- Even to be a block away, that's far for me to come here, everyday (001).

Yeah uh I come here for breakfast and lunch and uh that gives me the get up and go and do all my stuff or else I would just stay home. Because they wanted to give me a whole bunch of medication just for 30 days, I probably wouldn't take them because I still have medication at my place where it's on the shelf and it's staying there. So I come in now and that's better (023).
So the medication and the, the pill that I'm taking affects the food. Like, I can't take it on an empty else it'll, it'll hurt my body more hey. So I have to eat, like they say, they have to have more nutrition inside me. So the pill can fight the virus and keep it down (003).

Staff and Friends' Support

Social isolation can serve as an impediment to adherence and is predictive of decreased adherence to HAART (Altice et al., 2001). Conversely, having a confidante and receiving instrumental support are significantly correlated with reduced HIV stigma (Emlet, 2006) and hence better adherence to HAART. Most of the dialogue partners and half of the focus group participants indicated that support from the care providers, fellow patients and friends is important for their adherence to treatment:

Yeah it makes like, yeah it's family, eh, and you know it makes the drugs uh [HAART] a lot easier to take, just the contact with the people, so it's, it's the support I think-- I'll call it support-- makes a big difference (015).

I used to miss all my meds and stuff. And they get, they get it, like all the staff and everybody used to be on my case once in a while they would, they say, "You got take um, keep up with your meds, if you wanna stay healthy. You might get healthy again." (003).

I come here because I like the um, the staff and everything, the way people help. And I like the, the way things are run and for my um, my meds. I take my medication here. They help me keep up with my medication if possible. And they ask me why, sometimes when I do miss (010).

Mmm because they have some programs and....there's good people that work, good staff that work here and they're caring and they show, give you support and if you need someone to talk to or something. You know, sometimes I talk to because I have no family so I'm just on my own here, right (001).

I like it here. I like to, I like to come, I like the comfortability of being here with the people and they... you know everybody gets along with everybody. That's a good thing because if you-- if you don't feel comfortable you wouldn't go somewhere where you didn't right? (006).

When I started not taking my medication and, and I didn't, I didn't it was very uncomfortable. I was suffering and these staff pushed me towards uh, towards uh, just keep taking my meds (008).

Counselling

Counselling to improve adherence to HAART has been shown to increase length of life and modestly reduce HIV transmission (Zaric et al., 2008). The respondents in this study showed, with varied responses, that counselling does affect adherence to HAART:

And the people that, like, I go see my Drug and Alcohol counsellor, they, they have the, they have all the help here for that. And I was seeing them for a while um, until I got into a stable place where I didn't really have to see too much (003).

He's the drug counsellor. There's uh, uh, there's a men's group that you can go talk at and maybe get some of your stuff out of here. Um, some of the things I, but the problem is that most of the people don't wanna do it because they're, it doesn't change anything. Doing that doesn't change anything. You're still stuck with the original problem (002).

Methadone Maintenance Treatment

Methadone has been associated with decreased heroin addiction (DHHS, 2009), positive

prevention practice and the start of HIV treatment (Muga et al., 2004), and better adherence

to antiretroviral treatment schedules (Hernández et al., 2009). Five respondents in this study

offered the following views:

Like I come here every day to get my methadone. So that was why they decided to bring the medications here too. So um, other than that um, if I wasn't on methadone, you know, maybe I would miss um, some days and that. But because I gotta come here, you know, I, I um, I'm lucky that I have that setting so (009).

I know I was hooked on some substance downtown here, but now I don't do that no more. I've been clean. I was hooked on heroin. And now I'm on methadone. I don't do that anymore. And uh, right now I'm just taking my meds and that's it. Yeah (004).

I pick up my uh juice (methadone) here, so I take my meds at the same time. I've never missed (013).

A lot better. Before if I didn't get on the methadone program, I'd be trying to get my heroin all the time. It is hard to get it, to get my money together and all, to get it (021).

Um, at first I wasn't taking them every day. So um, I, what had happened was I got introduced to this pharmacy next door here and he dispenses my methadone so what, what they did was they decided to dispense my medication so I would get it every day. And since we've been doing that, it's been working for me (015).

However, some participants thought that even though the MMT program is available, there is unfairness in the way it is provided. This is consistent with research that has also shown that some patients believe that MMT services, if at all provided, are of a lower standard of care than those that other groups of patients receive (Parkes, 2009). One respondent commented:

I can't see why the health care system, like we're talking about, um, pain medication, MMT, okay. There's, they [doctors] say, "Well we don't wanna get you hooked on these drugs." I'm already hooked on worser drugs. What's the difference? Why? What makes me different than a 53 working male out there who gets these things? Why am I being told no? You know, when I'm asking you for your help and you say, "No well we can't do that because you live downtown east side." That doesn't make sense to me. You know, a working male outside the district would get the same thing, with no problem for himself (002).

Medication Pick-up routine and Outreach

Medication adherence and outcomes for persons with HIV/AIDS have been reported to be

substantially better with outreach intervention (Berrien, 2004). In this study, some patients

revealed that their adherence to the HAART had been greatly facilitated when they their

medications were dispensed to them by health care professionals through outreach:

I got outside, I mean to outreach upstairs and um, they provide um with....he's in pharmacy. Like um, he, I could come there everyday. I can take my medication (003).

They helped me keep up with my appointments and they got the outreach workers and stuff here that come help me. Like uh, um, sometimes when I didn't make it here, the nurses here come out and they, they, they'd come check up on me and they make sure I take my meds (024).

It's nice to have that outreach here - like if you're sick and you can't make it here and I think in most cases they'll deliver them. I think it's important for people to know that service is available, because if it wasn't obviously they could miss medications for two or three days and that can be pretty harmful, you know, and cause you to get even sicker than you already are (022).

Some patients were motivated to adhere to their antiretroviral regimens after receiving

help and support from a pharmacy that has a medication pick-up system in place:

Uh, just the way I get them at the pharmacy every day. That helps me take them that way. If I was to do them on my own I wouldn't be able to do it. I like the way it's done. I come to the pharmacy first thing in the morning and I take them, you know (004).

Availability of Funding and Services/programs

The availability of funding and services/programs can improve adherence to HAART

since with more funding comes more sustainable programs and services for people to access.

Almost half of the respondents in this study identified a lack of funding and services as a

factor contributing to adherence to HAART:

You can only take services that they provide you. There's no other service that they can more or less add - because they'd have to go through funding. That's, the services, uh they're pushing their services because what they have, the staff that they have, is, is pretty, they're pretty busy and that's the only time that they can really offer you things is from day to day (001).

And they have programs here but it's been like just a few programs now and just makes a lot of difference. Everybody's just so spread out now, there's nothing happening here but maybe once in a while a program happens here but not for real long and everybody just drifts away (008).

Now I see it and it's not, not really best assistance here anymore - like the funding is not there, the people are not there, like it used to be really a good running place, eh, but we have to just do so much for everybody now. You can't do everybody - more like it's a first come, first serve basis, eh? And it's very hard, I see it, I can see, I witness it eh (008).

Proper services are needed. You see, if you don't access to services, what's going to happen? You're just going to get sicker and possibly die (013).

Aboriginal-centred Services and Practices

A few participants in the study expressed that their experience with Aboriginal services

played a big role as to whether they took their medication or not:

They got traditional medicine there. So I go down every Tuesdays and Thursdays. Well uh, the way they do it, the way they sit in a circle, traditional medicine is like the Indian way, the Native way. And uh, doing it that way helped me much better. I learned from other people doing it that way. But the other way like uh, see doctors and pills, that's not the right idea pushing pills all the time like that, but it does help (004). I've been going there and they offered me lots of other help, and they got a whole bunch of these aboriginal classes to help out deal with everything. To learn my backgrounds and stuff. And now I mean, Aboriginal drumming and stuff. So it's really helping, helping, like I try to go to treatment and stuff....my Aboriginal drumming and stuff, and everything, it helped me out lots. 'Cause I found out, that was my cure to help me work my way up to the top. That was the missing pieces I needed. I'm one of the lucky people that did get all the, that uh, did listen to the staff here and worked my way up (003).

Since they started me on meds and I got appointments and I go to that traditional medicine thing, it helps me a lot (004).

Uh they've (Aboriginal services) been sensitive to my dietary needs, specifically, that's about all I can say about that (005).

Umm I still, I still believe in my culture and I still speak my language and some..., I use my cultural ways for, to help me through my health uh issues and, and this place helps me a lot (008).

Um, like um, spiritually. It's lifted my spirits up. Um, um, the cleansing of the um, medicines um, the smoke that we're using. Um, just the general way that we did it was like we open with prayer, close with prayer, um, had something to eat (009).

History of Trauma/ Residential School

The weight of historic trauma, and events of either the residential school or the child

welfare system, has been shown to lead to negative and destructive coping mechanisms, such

as substance abuse (Barlow 2003; Craib et al., 2003). Most dialogue partners and about a

third of the focus group participants said historic trauma had affected their adherence to

HAART; however, their views were diverse.

Drug abuse

A few respondents said that historic trauma led to them having pain and/or abusing drugs:

I guess so, in a way it does mentally, because I still think of it....emotionally and you feel, you think and it gives you pain and I guess in a reflex makes you do-- it made me into a alcoholic and drug addict because of that. I changed my life because I could, I went to school there and then I graduated but then I just-- because it's changed me. Hard to say (001).

I'm the kind that acts inwardly, so I punish myself. When I have these uh, anger, anger things right. Anger problems come up, I always do it inwardly. That's why I shoot IV drugs is because uh, the bad things in my life that have happened, I don't exemplify them out outside. I do that inside (002).

I think that it's affected me in more ways than one. Not, like, like indirectly, right. I don't like this. I see the way it made her feel and I kind of feel that pain (007).

Low self-esteem, Self-blame, Insecurity, Fear, and Resentment

A few others said that historic trauma resulted in them having low self-esteem, self-blame,

insecurity, fear, and resentment:

My partner wasn't in residential school but in the foster care system and really abused, sexually and physically, and he wasn't looked after.....just severe, severe abuse. So, the downside of that is he tends to blame himself for things. So he will look at things and make it his fault and, also, sometimes he has a pessimistic outlook on things (012).

It's simply, it's, it's uh, when a person doesn't feel worthwhile or have a, a goal or a reason to move forward in their lives, they stagnate. And like anything that starts to rot inside or stagnate, uh, it doesn't want that, the human psyche doesn't want to stay still. It wants to love. It wants to be part of something. It wants to be one of the sheep in a herd. When they're segregated they just, like this, left through residential abuse, HIV, drug usage, uh, being Native or being prejudiced upon. Uh, those things are all negative connotations that breed insecurity and fear, resentment. And uh, well the only way to not feel that way is to-- now the only thing we have in to, in society to not feel that way is a chemical, uh, that makes you feel numb for a while. That's the only thing we have to offer that can help. And it doesn't help. All it does is destroy, but it's the only thing that society has to offer (018).

Other effects

Three of the respondents said historic trauma did not affect their adherence to HAART.

One commented:

Racism and things that happen behind uh, behind the back. It's mostly what happened in the school and all that, what I've heard. But I've never been there so I don't know what it's all about. And what I heard is pretty bad. Yeah. Not really [In response to effect on health] because I haven't gone through it (019).

Two respondents said historic trauma resulted in development of survival skills:

Yeah at first it did for me because like um, like it was a decision that I had to make. I was using heroin so I mean I had to make a choice either if I wanna live or if I'm gonna keep doing this and maybe in a few months I won't be alive because the um, the way I'm going, you know, like I could die right. So I made a choice to quit drinking, you know I, I snapped out of it and I started taking my medications. Just affected me in actually just the decision, like either I wanna live or die kind of thing. And I chose to live, yeah (009).

But the upside, there's an upside to everything, is he's really....tough. He said to me, well we don't have anything to eat, "well I spent lots of time where I didn't eat for five days when I'd run away" - so, so that's the upside - it makes you really tough. So it's not just one way, plus he's really smart at the street level, he's smarter than I am but tougher in a way, so (016).

Medication-related Factors

Research has shown that there is an association between medication-related factors and

adherence to HAART (Duran et al., 2001; Kleeberger et al., 2001).

Complexity of Treatment

Many participants in this study indicated that, because of pill burden, fit to lifestyle and

eating patterns, complete adherence was a daunting task:

When I first started I was taking about seven, maybe thirteen pills a day just to keep the virus down and then they, they came up with this uh, three in one. And I've been taking that for a while and that's been helping me lots more, like just, just to take one pill a day instead of taking about twelve, thirteen pills. I like that (003).

Uh getting sick from them and I figure that's too many pills for me to take because I'm used to taking one pill all the time, not three or four. Before I was on many, more and more than that. And that was too hard for me, so I'm trying to get on one day pill. I think that would be better for me (004).

So, but, what I've gone from nothing to AZT mono therapy to 43 pills, 7 times a day where you've got to get up at 2 in the morning and take it and this one you can't take with food and that one you don't take with that one and just on and on and don't take grapefruit, to 3 pills a day all at once. I mean it's just remarkable - it's so easy now (012).

I was taking 27 pills at breakfast - 27 pills! I was so scared, I just, pill after pill after pill, I was just uh "why don't you start cutting it down alright" because things were-- but uh yeah that's uh, that was a real tough one (016).

I told my doctor, I said uh "I'm taking 12, 13 pills a day - I mean, I go to bed high and I wake up high and I don't like that feeling - can you?" and then he cut me down to five (021).

If I had to take that many pills I probably wouldn't. But I only take three, so, and I come here every day (007).

In (the) beginning for me, with my medications, there was some meds I had to take with food, others without, others uh twice a day, others once a day, uh....but now, but now I'm on a regime where I only take one dose or one set and that's it, a day, that's all. That's a lot easier for me (023).

Side effects

Three of the participants in the study indicated that medication side effects contributed in a

significant way to their adherence to HAART:

Um, I'm kind of like, the medication is kind of gives me uh, a, a really drowsy stuff. But, but other than that I know like, before I didn't like the, the effect from it but I'm learning to deal with it after I took it for so long (003).

Even though uh, my meds bother me, you know, I can't keep my, my meds, I'm scared to take them now because they make me so sick. Like every time I take them I throw them back up and I'm sick through the whole night. I can't sleep. This has been going on a week now (004).

The new pills I'm taking - they are more like driving me nuts. The other pills I took they didn't make me itchy or whatever. Just like every once in a while it seems like something will poke me here, inside, I can't catch it right - but boy, I'd like to take different pills (006).

Summary

This chapter has presented the results obtained from the study. The chapter has been thematically organised with results from both the dialogues and the focus group reflecting the story told in answer to the research aims and questions. The major topics covered have been patient factors, inter-personal factors, support structures, history of trauma/ residential school attendance, and medication-related factors as determinants to HAART adherence.

In the next chapter the factors that determine adherence to HAART in Aboriginal men in the DTES are discussed.

Chapter Five

Discussion

In this chapter, the factors that determine adherence to HAART in Aboriginal men in the DTES are discussed. A concise introduction is first presented. This is followed by the discussion of the overriding themes under the sections of; patient factors, interpersonal factors, support structures, history of trauma/ residential school, and medication-related factors. The limitations of the study are then presented followed by recommendations for future research. The chapter ends with a summary and conclusion.

Introduction

The relationship between Aboriginal status and HIV incidence and progression has previously been investigated (Lima et al., 2006). Since the eradication of HIV is not yet possible, persons undergoing treatment for HIV disease must take their Highly Active Antiretroviral Therapy (HAART) regularly (Ickovics & Meade, 2002a). There is disparity however, for Aboriginal persons when considering access to treatment for HIV. Not only do HIV-positive Aboriginal persons have sub-optimal access to HAART (Vancouver HIV/AIDS Care Co-ordinating Committee, 2000), they also have a shorter survival rates than non-Aboriginal persons (Lima et al., 2006). The Aboriginal population in BC alone makes up 13% of new HIV infections, many of whom are less likely to engage in effective care (Tu et al., 2008). This is despite the fact that, in BC, anti-retrovirals are distributed at no cost (BC-CfE, 2010). Furthermore, a recent report shows that HIV-related annual mortality rate stands at 9 percent (VNHS, 2008/2009). In men, this is disturbing since the proportion of men that report high risk behaviour is almost double that of females, with only half of the men actually using a condom in their last sexual encounter. Males are also less likely than females to access HAART (Tu et al. 2008).

Previous research on what influences people to adhere to HAART, particularly Aboriginal men in a disadvantaged community is limited. Therefore the purpose of this study was to investigate the determinants of adherence to HAART in Aboriginal men in the DTES of Vancouver and offer recommendations to improve adherence and help reduce deaths due to HIV/AIDS. The findings clearly demonstrate how challenging it is for HIV-positive patients to adhere to HAART.

The methodological approach of the Vancouver School of Doing Phenomenology, developed by Joan M. Anderson, was utilized in this study to investigate the phenomena (Anderson, 2001; Speziale & Carpenter, 2007). Data were collected using open-ended questions in one-to-one dialogues and through a focus group discussion. Participants were asked questions about what determines whether they take their medication or not and encouraged to describe their experience of being on HAART as fully as possible. These encounters were audio-recorded, transcribed and the qualitative technique of thematic analysis, which incorporates the inductive bottom up way approach (Braun & Clarke, 2006) was used for analysis of data.

From this study, factors that determine adherence to HAART in Aboriginal men were reflected in five over-riding themes: (1) patient factors, (2) inter-personal factors, (3) support structures, (4) history of trauma/ residential school, and (5) medication-related factors. Under patient factors, psychological factors, socioeconomic factors, knowledge and memory loss were seen to affect adherence. Interpersonal factors that affected adherence were stigma and discrimination, and patient/care provider relationship. Food provision, socializing, staff, counselling, medication pick-up routine, outreach, methadone maintenance treatment, the availability of funding and services, and Aboriginal-centered services were the support structures that, when present, improved adherence. A history of trauma and residential school

attendance led some respondents to engage in drug abuse, or have low self-esteem, selfblame, insecurity, and fear. Others, however, reported that, historic trauma resulted in "survival skills". Finally, the complexity of treatment and side effects of medications also affected adherence in some respondents. Individual factors are discussed here.

Patient Factors

Psychological Factors

Depression.

Individuals who have been diagnosed with HIV suffer from high rates of depression (Turner et al., 2003) and other emotional responses to stress are possible, such as anger and withdrawal. Depression itself may present with the symptoms of self-neglect, despair, apathy, irritability, pessimism, forgetfulness and generally an inability to function (Anderson et al., 1982; Salzano, 2003) all of which may result in decreased adherence as exemplified in some of the responses by participants in this study. The results from this study are consistent with literature that indicates that patients presenting with depressive symptoms are more likely to have an early discontinuation or non-adherence to HAART (Leserman et al., 2002; Simpson et al., 2006). This reduced adherence may lead to a decline in CD4 counts resulting in disease progression, and death in individuals with HIV (Singh et al., 1996). These outcomes can therefore be as a result of the effect of depression on adherence. Apart from anger, despair, and forgetfulness, as exemplified in this study, depression among those on HAART can result in non-adherence as patients give up and may even refuse treatment altogether (Blumenfield, Milazo, & Wormser, 1990). Also, according to Lyketsos and colleagues (1996), depressed individuals may also be less motivated to take their antiretrovirals. A hypothesized causal effect between poor adherence and depression is difficult to ascertain, however, since less than optimal adherence may lead to depression, and yet on the other hand

depressed individuals may be less motivated to take their medication (Nakiyemba et al., 2006). It may also be that, given the chronic nature of the HIV infection and the complicated treatment regimen, constant intrusive thoughts around the illness and treatment, as shown in some of the participants, may increase stress and depressive symptoms in HIV/AIDS patients (Schonnesson et al., 2004). Furthermore, one can also argue that the resultant disease progression may be due a decline in CD4 counts due to the effect of depression on the immune system (Herbert & Cohen, 1993; Singh et al., 1996).

The issue of whether stress causes depression or vice versa is another area of concern. Because both can be products of each other, it can be almost impossible to determine which has a more important role in affecting adherence. Depressed patients often undergo increased numbers of life events secondary to their affective illness and depression-related reduction of cellular immunity could possibly be a result of the effects of life stress, not depression. On the other hand, stress can also cause depression through an increase in glucocorticoid hormone activity that leads to a depletion of norephinchprine levels (Salzano, 2003). The hormonal activity results in the individual being less attentive, emotionless or inactive. For those on HAART, therefore, medical concerns should be considered a substantial marker for depression (Schonnesson et al., 2004) since early diagnosis and treatment of depression may lead to better adherence levels.

Alcohol and drug addiction.

Active drug use, including alcohol use and abuse, is prevalent among HIV-positive individuals (Bryant, 2006; Tyndall et al., 2001) and has been frequently linked with poor adherence to HAART (Cook et al., 2001; Gorbach et al., 2006; Sankar et al., 2007). The results from this study are consistent with this literature as most respondents indicated drug addiction was a major contributing factor to reduced adherence to medication. After taking

drugs or drinking alcohol one could become inattentive or have a reduced concentration level leading to forgetting medication. In line with an observation by Hartel and Schoenbaum (1998), the decreased adherence to HAART in this population may correlate with the degree that drug use disrupts one's normal daily activities, in this case taking medication at a given time, rather than with the effects of the drugs themselves. This could explain why some respondents indicated that when faced with an immediate choice they would take the illicit drugs first and probably hope to take HAART later.

This attitude may not necessarily be due to respondents always going out of their way to look for and purchase illicit drugs. It may be because some may view taking illicit drugs as an acceptable practice. This was alluded to by some of the respondents and is echoed by Newnham (2005) who states that, for much of the past decade, an open drug scene has been located in the centre of the community (downtown eastside of Vancouver) and illicit drugs are currently cheap and accessible. Subsequent progression of disease and the occurrence of death in HIV/AIDS can therefore be attributed to low adherence secondary to alcohol and drug addiction. Also, the high rates of death of HIV/AIDS patients could be a direct result of drug overdose. A review of coroner's files for deaths between 2001 and 2005 found highly elevated overdose death rates and levels of premature mortality among First Nations people in BC compared to the general population (Milloy et al., 2010).

On the positive side, however, in one prospective study, patients whose alcohol or drug use declined demonstrated improvements in adherence (Lucas et al., 2002). Literature also indicates that, when IDUs are not actively using drugs, efficacy of HAART in the IDUs is similar to that seen in other populations (Copenhaver et al, 2003). Given these reported associations, and the fact that IDU, illicit drug use, and alcohol, are modifiable behaviours, there is hope in that successful targeted interventions could potentially improve disease management and help delay disease progression. The first step in provision of care and treatment for alcohol and drug abusers should be the recognition of the existence of a community drug problem. To address the complexity of challenges experienced by substance users and fully engage them into health care, the provision of services that respond to a patient's immediate needs and facilitates entry into, as well as retention in addiction, recovery and HAART may be necessary (Montaner & Volkow, 2010). We need also to not only care for Aboriginal drug users but also provide justice, as well as healing, for all people who use illicit drugs.

Fear of getting more sick or dying.

The fear of dying has been shown to be prevalent in HIV/AIDS patients (Meng, 2008). An acceptance of the role of medication in avoiding severe illness and death (Lewis et al., 2006), as well as a history of opportunistic infection and more advanced disease or symptom severity (Bond & Hussar, 1991; Singh et al., 1996) have also been reported to contribute to high adherence (Lewis et al., 2006). Most of the study participants' responses, especially those who had been more sick or had been admitted to hospital before, and those who had seen a friend die of HIV/AIDS, were consistent with this literature and also in line with the health belief model.

It was noted however that only one respondent expressed a general will to live, irrespective of any fears, as his motivation to take medication. One might wonder whether patients would still adhere to their HAART when they continually notice that their viral loads are undetectable and that they are healthier. Those on HAART may need to be cautioned about this because these HIV monitoring indices may transiently improve despite sporadic adherence and this may reinforce a patient's level of overall poor adherence whilst making the patient liable to development of drug resistance. Furthermore, even though a strong and

lasting suppression of HIV viremia may result from HAART, if therapy is interrupted, the replication of HIV resumes (Buzón et al., 2010).

Not caring, procrastination or being too busy.

A few respondents indicated that procrastination, being too busy or just not caring contributed to poor adherence to HAART. This is consistent with previous studies by Metsch, Pereyra, & Brewer (2001), Westerfelt (2004), and by Conway (2007) that showed that HIV/AIDS patients may miss treatment due to these reasons. Taking HAART may be at the top of one's priorities but, because patient's may be anxious about the availability of money to buy daily necessities, and their access to food, they may end up procrastinating, being distracted or being busy either looking for food or money, or going to work so they can get paid, and may end up forgetting to take HAART altogether. It may therefore be important to primarily address these daily struggles in order to enable patients to adhere more to HAART.

Accepting the challenges and consequences of taking medication, followed by a patient's commitment to taking their medication from the start, may be important for others to emulate and may lead to better adherence. According to Lewis and colleagues (2006), individuals who adopt a realistic future outlook, and recognise the need for personal accountability to regain control over their lives and their health and to confront the disease, adhere to the medical regimen better (Lewis et al., 2006). Individuals on HAART may benefit from being encouraged to therefore adopt a positive attitude, to see meaning in their lives, in the hope that this will increase their adherence to HAART.

Traditional beliefs.

The responses from the study clearly showed that Aboriginal peoples have ancient culture specific philosophical foundations and practices which continue to provide them with

guidance in everyday life. This is consistent with literature that has shown that traditional beliefs affect one's ability to cope with HIV/AIDS and its treatment (McLeod, 2004; Montour, 2000). This cultural belief system, for many Aboriginal people, continues to be the framework from which they live. In their healing process the framework guides those who experience physical, psychological, emotional, or spiritual distress (Poonwassie & Charter, 2001) and gives them meaning and purpose in life.

Aboriginal peoples are well aware of the positive effects of solutions which have originated from within their own cultures (Couture, 1987) and have argued that these have proven to be most successful in meeting their peoples' needs and in facilitating change (Poonwassie & Charter, 2001). Considering the responses given, and in agreement with Absalon (1993), I therefore think that all those who collaborate with Aboriginal communities in healing initiatives may need to understand and accept that Aboriginal peoples have practised viable traditional healing methods throughout their history, and that these methods need to be recognized.

Socioeconomic Factors

Employment status.

Employment status has been indirectly associated with low adherence to HAART (Kleeberger et al, 2001). Some of the participants in this study expressed the view that, because of being unemployed, they have difficulty meeting their food needs and purchasing other daily necessities, they thus spend a lot of time looking for money leaving themselves with no time to take their medication or leading them to forget to take HAART. Not having money to buy food may cause some patients not to adhere strictly to HAART since some of the medication needs to be taken with food. The low adherence could then lead to lower levels of health status and increased mortality as seen in one study by Adler and Newman

(2002). One could argue further that unemployment could be blamed for lower levels of adherence in terms of stress caused by job insecurity (and other local community stress) which could lead to a diminished intent and/or capability to follow HAART according to proper dosage and timetable (Fong et al., 2003).

Having said this, a recent large systematic review found that there seemed to be a positive trend among components of socioeconomic status and adherence to HAART in some studies. However, in most of the studies, no conclusive support for existence of a clear association was established (Falagas et al., 2008). Specifically, employment status was not found to be an independent factor associated with adherence, in the majority of the studies. One can therefore then argue that having a busy workload might also be an impediment to a patient's ability to adhere to HAART (Fong et al., 2003), therefore suggesting an adverse association between adherence to HAART and a demanding working schedule. In this study, however, most respondents were on disability allowance, with a small percentage being either employed seasonally, unemployed, or just working part time. Furthermore, in this study, those who were volunteers said that volunteering actually kept them off the street and away from illicit drugs, whilst being in a place where they could get food and medication, hence leading to better adherence.

In this study also, I find it imperative to note the demographics in order to understand the situation in which these participants live as this could help understand the difficulties in adherence. For example, the fact that the number of people who are unemployed in the DTES is higher than in any other part of Vancouver. Without meaningful and adequately paid employment, many people continue to be dependent on the social service organizations located in the area for shelter, food, clothing, and other forms of assistance. This lack of local employment opportunities should be seen, on many fronts, as especially problematic in a city

with a high cost of living like Vancouver (Newnham, 2005). In order to fix the problem of adherence to HAART in this resource-poor setting of the DTES therefore, all these factors may need to be taken into account. Free treatment may simply not be enough.

Housing.

Access to safe, affordable housing helps people living with HIV/ AIDS and marginalized people to adhere to HAART, as shown by a few respondents in this study. This is consistent with previous studies which showed that access to housing improves access and adherence to HAART, which lower viral load and reduce the risk of transmission (Holtgrave & Curran, 2006). The direct negative effect of homelessness given by one of the respondents, that when one is homeless, one does not get much sleep but when they do eventually sleep, they might do it through medication time, and then forget if they took their HAART or not, is striking. Patients may indeed find it difficult to balance their need to sleep, as well as their need to eat, against taking HAART.

One other explanation of why those who are stably housed adhere more to HAART may be that having a home is associated with fewer risk factors for non-adherence: the stably housed are less likely to use illicit drugs, for example, than homeless persons (Kidder et al, 2008). This is in line with research that has shown that, over time, persons who improved their housing status reduced risk behaviours by half (Aidala, et al., 2005).

One could argue that the DTES has shelter facilities that many people could use and therefore homelessness should not be an adverse factor with respect to HAART adherence. However, it has been shown that some shelters turn people away because of a lack of space (Newnham, 2005), or people may not be willing to go into one because the shelter may be unclean (infested with bed bugs, rats, etc.), or unsafe (presence of drugs, gangs and other predators) (Spaxman, 2009). Also, research has shown that proven HIV risk reduction interventions, as well as adherence improvement, are less effective among persons who are homeless/ unstably housed than among their housed counterparts - including counselling, needle exchange, and other behavioural interventions (Wolitski et al., 2007). The VNHS, however, through its programs continues to work hard to help patients get housing units by helping them make applications and set up appointments to BC housing and various other organizations (VNHS, 2010). However, the waiting list for these units keeps getting bigger suggesting that need surpasses supply.

Other Factors

Knowledge of drug resistance or interactions.

The fact that most respondents in this study indicated they had some good knowledge of how drug resistance can develop, and knowledge of how alcohol affects medications, and that this led them to adhere to HAART, is important to note. These responses were consistent with research that shows that knowledge of drug resistance may lead to high levels of adherence to HAART in treatment-naive patients resulting in durable viral suppression and no clear evolution of drug resistance (Green, 2004). Knowledge should however be imparted on patients constantly if adherence levels are to improve. This knowledge may include the fact that patients taking HAART intermittently or at reduced doses often experience suboptimal drug levels thus increasing the likelihood of drug resistance (Miller et al., 2003), and that resistance to one drug is frequently associated with cross-resistance to other members of the same class (Kozal, 2004) thus limiting future treatment options.

The fact that respondents in this study expressed that knowledge of alcohol interactions with HAART helps them take medication should be taken with caution when counselling all those who drink alcohol and are on HAART. This is so because other research has shown that frequent drinkers could be more concerned about potentially harmful interactions between alcohol use and their medication, and may thus be less adherent to HAART (Parsons et al., 2007). Furthermore, heavy drinkers may also see fewer benefits from taking their medication. There is therefore the need to strengthen advice and information, ensuring that each patient has the correct information with respect to development of resistance to HAART, as well as its interactions with alcohol, needed to support reasoned decision making and adequate adherence.

Patients who do not worry about missing medication because their CD4 counts stay at high level may be expressing what may be a lack of adequate knowledge regarding the antiretroviral medication, such as not knowing the proper way to take the pills or not knowing what resistance entails. The danger is that others may take these "drug holidays," believing there would be no detrimental effect to their health. Such "drug holidays" only give the virus ample time to mutate and become resistant to the medication. According to a recent study, people who take drug holidays are nearly three times more likely to die or develop serious infections than people who do not interrupt therapy (El-Sadr et al., 2006). Because of this, discontinuation of HAART in HIV-positive subjects with complete virologic suppression should be conducted cautiously when certain anti-retroviral medications are in use and/or wish to be used in case of treatment resumption (Barreiro et al., 2003). Patients may need education on medication regimens so they can adhere better to HAART.

Memory loss.

The results of the study were consistent with studies that show that memory loss in HIV/AIDS patients is associated with low adherence to HAART (Meyerhoff, 2001; Selnes, 2005). Other studies have also shown that HIV-positive individuals were much more likely to complain of "difficulty thinking" than negative individuals (Becker et al., 2004). This may be

a compounding but not so obvious factor in some patients. This memory loss could be secondary to HIV damage to cells in certain sections of the brain.

Although only one respondent in this study attributed decreased adherence to memory loss, I felt it important enough to deserve mention. Patients with memory loss may be wrongly seen in the same realm as those who show low adherence due to forgetting medication following drug or alcohol abuse. It may be important therefore for care providers who notice memory loss in patients to look carefully, investigate and rule out other causes of memory loss (Selnes, 2005). Memory loss secondary to HIV disease progression should not be missed as this would mean missing an opportunity to delay progression by instituting measures, such as medication assistance, to ensure better adherence to HAART. Pin-pointing which memory symptoms may be specifically related to HIV infection (as opposed to Alzheimer's disease, depression, or drug related causes) is still challenging, however, because of the increased survival and aging of those living with HIV/AIDS, this exercise should therefore be considered seriously. Regardless of HAART status, a careful evaluation of a patient's medication regimen must be performed to rule out cognitive impairment resulting from medication side effects (Becker, 2004).

Interpersonal Factors

Stigma and Discrimination

Stigma and discrimination was one of the main determinants to adherence in this study. This is consistent with literature that holds that this factor adversely affects the numbers of people choosing to be on treatment when HIV-positive (CAAN, 2004), and lowers adherence to HAART (Rintamaki et al, 2006). Most HIV/AIDS patients are discriminated against because they have become infected through a behaviour or sexual orientation that is stigmatized (for example, injection drug use [IDU], or gay respectively) or belong to a culture (Aboriginal), that is vulnerable to stigmatization.

Stigma and discrimination in a health care facility.

Stigma and discrimination coming from health care providers, in particular, is worrying. Studies have shown that those who use illicit drugs are medically underserved (Chitwood et al., 1998; Wood et al., 2004). Active drug users, even in a setting providing free HAART, experience difficulty obtaining care for HIV-related illnesses (Cunningham et al., 1995; Strathdee et al, 1998). HIV/AIDS-related discrimination in health care therefore continues, particularly for Aboriginal people. There may be stigma, as shown by one respondent who said he may not go in to get his medication for fear of being treated with disdain. Some health care providers may not be knowledgeable about HIV and Aboriginal history leading to stigma, and there may also be problems with confidentiality in small communities because everybody knows everyone else. Because of these reasons, one may have low adherence to HAART.

A positive, trusting relationship with health care personnel may be fundamental to the provision of non-discriminatory care. Because the discrimination experienced by Aboriginal people with HIV/AIDS is sometimes due to lack of knowledge or sensitivity to Aboriginal cultures, traditions, and socioeconomic conditions, and secondary to negative stereotypes about Aboriginal people (Larkin et al., 2007), knowledge of the phenomenon of AIDS stigma is important for health professionals because of its serious consequence of being a barrier to appropriate treatment (Link & Phelan, 2006; Rintamaki et al, 2006).

Stigma and discrimination on the street.

The systemic and individualized discrimination, experienced by Aboriginal people associated with HIV/AIDS in particular, contributes to the disproportionate impact of

HIV/AIDS on Aboriginal communities (Matiation, 1999). Discrimination on the streets could be associated with misunderstandings or lack of knowledge about HIV/AIDS, and may be reinforced by other social problems. The anger that Aboriginal people feel as a result of their discrimination can be internalized, resulting in a high degree of self-destructive behaviour. The feeling of not being wanted in society, as exemplified by some respondents, may lead to low self-esteem, and drug and alcohol abuse which may in turn lead to low adherence to HAART.

Stigma and discrimination on the reserve.

Stigma may induce psychological stress and result in reluctance to access health services (Des Jarlais et al., 2006). Members of a reserve community may refuse visitation from someone with HIV for fear of being infected believing that HIV might be contagious, as explained by one of the respondents in this study. Some patients may feel unwanted because of AIDS phobia and homophobia on the reserve and may keep away from family due to concerns about exclusion, and threats of violence against oneself.

Two-spirited people (gay, lesbian, bisexual) for example, may not generally trust the confidentiality of on-reserve health services and due to discrimination in rural environments, often leave for cities where they find anonymity but unfortunately experience cultural trauma and isolation (Brotman, et al., 2002). According to Matiation (1999), two-spirited people may be seen as unhealthy, sinful, and/or unbalanced. In some reserve communities, a visitor with HIV/AIDS may also be seen as a source of shame for the family visited. Patients may therefore feel they are not wanted in their own communities and have a low sense of self-worth which may lead them not to adhere to HAART. Aboriginal communities at large, especially on reserve, may therefore need to be exposed to information about HIV/AIDS so that they can gain more understanding and lessen stigma and discrimination.

Patient-Care provider Relationship

The data from this study demonstrate that the patient–care provider relationship influences medication adherence in HIV, even when the patient factor of substance abuse is considered. In addition, some patient–care provider relationship factors served as protective, and some served as risk factors for adherence to HIV medication. The responses are consistent with studies that have shown that the type of patient-care provider relationship affects adherence to HAART (Demmer, 2003; Schneider et al., 2004).

Some respondents may not adhere to their treatment as they felt that their physicians refused them certain medications because they were drug addicts. Others said that there was this notion that one could not be trusted enough if he were a drug addict. This may have left these patients dissatisfied with the service they were getting and could have led them not to adhere to HAART (Roberts, 2002). A relationship of trust between patient and care provider could foster a more revealing and deep discussion regarding missed medications and struggles with adherence (Ickovics & Meade, 2002a/b; Ingersoll & Heckman, 2005), more confidence in HAART, and working towards a mechanism for better adherence. Others may not adhere to HAART if they did not perceive the provider as open, respectful, understanding, empathic and showing genuine interest (Simoni et al., 2003). It should be noted however that, whilst a simple trusting patient-care provider relationship is paramount in promoting better adherence to HAART, other factors such as social and cultural realities, and power dynamics, may need to be taken into account.

Support Structures

Availability of and Access to Food

Food insecurity (lack of access to food of sufficient quality and quantity to perform usual daily activities) and undernutrition are increasingly recognized as factors that are important

in the health and livelihoods of individuals living with HIV infection in poor settings (Gillespie & Kadiyala, 2005). Most participants in this study thought the acquisition of adequate nutrition contributed to better adherence to HAART. The availability of a support system, such as a food program, with the knowledge of the importance of good nutrition and that some medications needed to be taken with food, helped them adhere to treatment. These responses are consistent with research that shows that food assistance is associated with improved food security, increased weight, and improved adherence to medication among people living with HIV/AIDS (Ivers et al., 2010). Apart from the reason that food is hard to get in an impoverished community like the DTES, the fact that some antiretrovirals increase appetite, and may be a fear of getting drug side effects, may lead people to want to have a decent meal before they take their medication.

Attention to adequate nutrition during HIV care, starting with the provision of enough food, can help strengthen the body's defence against the virus, reduce progress from HIV to AIDS, reduce some side effects of antiretrovirals and promote adherence to HAART.

Staff and Friends' Support

Studies have indicated that people who are on HAART and who receive adequate emotional support and the correct affirmations from their health care providers and significant others are better able to adhere to their medication regimens (Morse et al., 1991). Furthermore, having a confidant and receiving instrumental support are significantly correlated with reduced HIV stigma (Emlet, 2006) and hence better adherence to HAART. Most of the study participants' responses were in agreement with this previous literature as they indicated that encouragement and support from care providers, fellow patients and friends is important for their adherence to treatment as most patients may feel comfortable in an environment with fellow patients and staff who better understand the disease. There may also be less stigmatization in such an environment, like the VNHS clinic, and therefore less shame attached to being HIV-positive. Patients are therefore able to be open about day-today problems they may be facing and about their treatment. In addition, those who are on HAART can often find very valuable support from staff and fellow patients, as indicated by some respondents, helping them to stick to their medication. It may also be that, for some patients, just seeing their friend's positive adherence behaviours improves their own adherence to the antiretroviral regimen.

Other research has shown that adherent patients have been found to be those who have family support (Lewis et al., 2006). However, most of the respondents in this study had no contact with their immediate family and, some of those who did, as discussed earlier, were pushed away showing that social isolation can serve as an impediment to adherence and is predictive of decreased adherence to HAART (Altice et al., 2001). Providers should therefore always ensure that patients, and their families, are given adequate adherence information and support in order to reduce chances of patients falling behind on their HAART.

Counselling

A diagnosis of HIV in the face of limited resources in someone living in the DTES Vancouver may cause a lot of stress and emotional difficulty as one struggles to cope. Counselling can therefore play a vital role in helping promote better adherence levels for those who are on HAART as it has been shown to increase length of life (Zaric et al., 2008). Most respondents in this study indicated that counselling had a positive effect on their adherence to HAART. This observation is consistent with studies such as that of Knobel (1999) who reported markedly improved HAART adherence levels and reduced viral loads in patients receiving individualized counselling (Knobel, 1999). The success of counselling in improving adherence may be because it involves detailed information about drug and alcohol

abuse, as indicated by some respondents, as well as HAART information and the adaptation of treatment regimens to suit the patient's lifestyle.

One respondent however thought that counselling for drug abuse in particular does not help as it does not solve the original problem. Counselling may be provided but optimal treatment of the substance-use disorder may not be available at the time when it's needed and, there may be problems with waiting lists and capacity (Spittal et al., 2007). On the other hand, even though communities may have enough local resources to provide counselling, this may not be the reality for most Aboriginal communities, and all Aboriginal clients may not have access to Aboriginal counsellors. The counselling provided may therefore not be culturally sensitive and hence may not solve one's problem. Merali (1999) observed that, even when ethnic matching is achieved, it may not eliminate all value conflicts.

An effective and helpful counsellor may therefore be called upon to use a process which is consistent with the client's values such as the one reported in a study by Pradier (2003) that led to significantly improved HAART adherence levels. This counselling approach was based on the principles of motivational psychology, client-centered therapy and the use of empathy to enhance participants' self-efficacy. The intervention focused on cognitive (knowledge, beliefs, assumptions about medication), emotional (uncertainties, loss of hope, anxieties), social (stigma associated with the disease) and behavioural (plans to achieve treatment adherence) determinants affecting adherence (Pradier, 2003).

According to Duran and Duran (1995), both Aboriginal and non-Aboriginal counsellors must also understand that many Aboriginal clients have been so acculturated that many times the focus of the therapy is merely to help make sense of their lifeworlds from a traditional perspective by reconnecting them to a traditional system of beliefs. Also, for counsellors, sometimes it may be unnecessary to advocate for individual client responsibility because traditional Aboriginal therapeutic approaches usually involve relatives and community members (Herring, 1989; McCormick, 1997). Some Aboriginal people believe that all things are interdependent (Lafromboise, Trimble, & Mohatt, 1990); therefore, just as one is connected to the earth and universe he/she is connected to his family and community (Epes-Brown, 1989). As such, excessively individualistic behaviour is considered to be one cause of illness and can only be treated by family and community therapy (Lafromboise, 1988). Furthermore, counselling approaches that are not Aboriginal may not necessarily deal with spirituality.

In order to begin to meet the needs of all Aboriginal clients, therefore, it may be vital to identify the critical components of the counselling process/method which help to facilitate traditional Aboriginal ways, de-colonization and empowerment (Poonwassie & Charter, 2001).

Methadone Maintenance Treatment (MMT)

Respondents in this study indicated that methadone treatment has helped them get off drug abuse and stabilize on HAART. This is in agreement with studies that have shown the association of methadone treatment with decreased heroin use, positive prevention practice and the start of HIV treatment (Muga et al., 2004), improved adherence to antiretroviral treatment schedules (Hernández et al., 2009), viral load suppression and positive CD4 cell count response (Palepu et al., 2006). The fact that patients get to go to the VNHS clinic, or to the pharmacy next door, on a daily basis to get their methadone treatment helps them adhere to HAART.

There is, however, a downside to this in that MMT may not work for others and therefore proper assessment and monitoring is warranted for those in any given program. Methadone, because of its pharmacologic effects, may interact with antiretroviral agents. It is therefore important to anticipate interactions between methadone and antiretrovirals, and to adjust doses accordingly (Antoniou et al. 2002). Interactions that precipitate opioid withdrawal may trigger relapse into heroin use, diminish the effectiveness of either or both therapies by causing opiate withdrawal or overdose, increased methadone toxicity, and/or decreased antiretroviral efficacy, and foster distrust of medical providers and result in an unwillingness to take HAART (Dobkin, 2005).

Another problem is that, despite expansions in the availability of MMT in BC in 2000, and its demonstration of successful opiate addiction treatment and HIV prevention (Gibson et al., 1999) physicians in public health clinics in Vancouver recently reported an inability to meet patient demand (Buxton, 2007; Mehrabadi et al., 2008). This is because of an overwhelming increase in the number of patients needing MMT, from less than 3,000 in 1996 to almost 10,000 by 2006, resulting in the need for service exceeding available capacity (Reist, 2010). This problem is complex, however, because some patients have reported a loss of faith in the MMT citing perceived unfairness on the part of some clinics or failure by some clinics to open overnight (Parkes, 2009).

Despite these problems, integrating opiate addiction care and HIV care may provide improved health outcomes for this vulnerable population, it should continuously be advocated for. Other ways of supplementing MMT are therefore needed. Krüsi and colleagues (2009) proposed understanding low HAART adherence with emphasis and acknowledgement of the influence of social, structural, and organizational factors, and a move away from individually focused interventions (Krüsi et al., 2009). The future therefore may be bright but, there is still a lot of work to be done.

Medication Pick-up and Outreach

Respondents in this study reported that their adherence was facilitated by medication pickup and outreach. This is in line with research that has shown that HAART adherence and outcomes for persons with HIV/AIDS have been reported to be substantially better with outreach intervention (Berrien, 2004) or through a medication pick-up system (Lucas et al., 2004).

Outreach by nurses, and care providers alike, is particularly useful for patients who may be sick and not be able to leave their houses to collect their medication. This outreach is not only valuable but for promoting HAART adherence, it also saves lives. A medication pick-up system is also a good way to promote adherence especially in this community because many patients have to come in on a daily basis anyway to get their meals and, since most live in the DTES, transport costs may not be a problem. Individuals may be able to come to the health facility for their medication with relative ease (Hardon et al., 2007).

The practice of medication pick-up and outreach may prove particularly useful for drug users. A few studies document the difficulties IDUs often have in accessing, remaining in and deriving the full benefit of HAART as well as the potential for overcoming these obstacles through substance use treatment, outreach programs, and medication pick-up systems (Lucas et al., 2004). According to Needle and colleagues (2005), IDUs can be successfully integrated into HAART adherence promotion using outreach care providers, whose own background may include substance use and HIV infection.

Availability of Funding and Services/programs

Almost half of the respondents identified a lack of funding and services as a factor contributing to low adherence to HAART. This is consistent with studies that have shown that a lack of funding and services may lead to decreased quality of care for HIV/AIDS

patients in the long term and ultimately affect adherence to HAART (Van Dyk, 2008). Furthermore, a lack of staff can lead to an increased workload, burnout, absenteeism and low staff morale. Without funding, there will be fewer staff and volunteers to provide services, fewer programs and services that patients can access, and patients will drift away resulting in lower adherence levels and, as explained by one of the respondents, patients may get sicker and die.

Furthermore, less funding will result in increased infection HIV rates since, with fewer programs, people will be spending more time on the streets exposed to drug abuse and other risky behaviours. Another danger is that reducing community programs for marginalized communities, such as the DTES, will reduce the quality of care that infected patients already receive. Reduced funding has a negative impact on organized and supervised HIV/AIDS care. Provision of more funding and more services and programs for HIV/AIDS needs to be seriously considered if adherence levels to HAART are to be improved.

Aboriginal-centred Services and Practices

A few participants in the study attributed their adherence to HAART to, in great part, their involvement with Aboriginal services. They mentioned using traditional medicine (as opposed to just using modern pills alone), sitting in a circle, speaking their language, learning from other people, having Aboriginal classes, drumming and praying, having dietary needs met, and their spirits lifted through cleansing as things that helped them take medication.

In some ceremonies, individuals or community do not only connect with their ancestral roots and belief systems (Hart, 1997), they may also be helped to develop specific attributes such as courage, confrontation of personal fears, or meeting of difficult personal goals. Adherence to HAART may be better because participants may feel supported, encouraged, and accepted, and have a sense of reassurance from others. Participating in ceremonies may

also have helped improve their spirit, helped them feel better and take their medication (McCormick, 1997). Some Aboriginal people feel further away from creation and the Creator because of the influence of living in today's cities. Using water and smoke in the ceremonies may have been a way to re-connect with nature, and therefore getting back to creation and the Creator (Poonwassie & Charter, 2001). Reconnection with natural elements may have helped participants to feel cleansed and stronger and hence helped them take their medication.

Traditional approaches to supporting and/or healing are reflected in the methods used not only by respondents in this study, but also in most Aboriginal communities today. Traditional healing ceremonies have been shown to be effective in healing (Jilek, 1982; McCormick, 1997). Through ceremonies, elders and traditional teachers present traditional philosophies (Régnier, 1995). Learning traditional teachings, participating in ceremonies, and modelling of appropriate behaviours may foster integration and application of learned cultural imperatives (Poonwassie & Charter, 2001). Appropriate behaviours in this sense may include, for example, staying away from illicit drugs and adhering to HAART.

Aboriginal people who follow the teachings of the medicine wheel may become ill when they live in an unbalanced way (Montour, 2000). Healing, as the search for balance and restoration of harmony, is understood to include four aspects of a person, as reflected in the medicine wheel; the physical, the emotional, the intellectual, and the spiritual (Absalon, 1993). Imbalance within the medicine wheel (e.g., the loss of traditional values) causes disorder and unsettles a person's life resulting in ill health (Montour, 2000). For Aboriginal people, balance then is therefore important because they consider the world to be a balance of human beings, the natural environment, and transcendent forces (Hammerschlag, 1988). Teaching and sharing circles, and participation in ceremonies, may need to be considered and encouraged in today's world if adherence to HAART is to improve. It should be noted, however, that the validity of traditional ceremonies as a component of life or healing is not accepted by all Aboriginal people (Poonwassie & Charter, 2001). Because of this, participation should be seen as a personal choice and one's decision on whether or not to choose a traditional path to healing should be respected in all circumstances. Also, as noted earlier, because Aboriginal therapeutic approaches usually involve family and community members as part of the healing process (Herring, 1989), maybe health delivery approaches like the medicine wheel² need to be considered in the quest to improve adherence to HAART (McLeod, 2004). With the recognition that the answer may not always be in tests, pills, or specialists, but may be in finding and dealing with inner pain, in learning how to talk and to trust, in seeking balance and in receiving counselling, implementation and respectful observance of the medicine wheel approach may prove advantageous. It may be more effective in providing patients a framework to identify and deal with the causes for their symptoms and, by expanding from the biomedical to the holistic model, it can improve quality and cost-effectiveness of treatment as it encourages patients to undertake their own journey to wellness (Montour, 2000).

History of Trauma/ Residential School

The participants' responses were consistent with literature that shows that historic trauma, and a history of residential school attendance, affect adherence to HAART (Barlow 2003; Craib et al., 2003). This, as shown in some of the responses, was due to development of behaviours that were seen as mostly dysfunctional but sometimes healthy at the same time, as

 $^{^2}$ The term "medicine wheel" is not a native term. Initially it was used in the late 1800's and early 1900 by Americans of European descent (Laframboise & Sherbina, 2008) although it is identified as having come from the Indigenous cultures of the Great Plains (CAMIMH, 2010). The medicine wheel is an ancient symbol of the life, health and values of an individual, community or Nation used by many First Nations and Métis, and by many different cultures throughout North America. However, it is not used in all the traditions of all First Nations and Métis. Neither is it an Inuit concept nor is it used in Inuit cultural practices in any way (CAMIMH, 2010).

Wesley-Esquimaux and Smolewski (2004, p. 3) assert "they [may] help the individual survive untenable situations, and unhealthy because the individual invariably ends up imbalanced and/or continues to blame himself or herself for the abuse experienced, may lack trust and may act out the abuse experienced in a variety of dysfunctional ways".

Participants in this study thought their adherence could be reduced through the development of negative and destructive coping mechanisms, such as substance abuse. It may also be because those who had experienced historic trauma in one way or another exhibited low self-esteem, self-blame, insecurity, fear, and resentment all which may have led to a feeling of not being wanted/ accepted in society and a negative outlook on life which led to decreased adherence to HAART.

Drug abuse

Respondents who resorted to drug abuse thought that it would relieve their psychological and emotional pain that they suffered, and that they continue to experience from historic trauma. The sense of hopelessness alluded to by the respondents may have caused them to no longer care about their health (Vernon, 2001). Historic trauma therefore may indirectly lead to decreased adherence through drug abuse. The ways in which drug abuse may lead to low adherence have been discussed earlier.

Low self-esteem, Self-blame, Insecurity, Fear, and Resentment

Those who developed low self-esteem, self-blame, insecurity, fear, and resentment said these attributes were as a result of either sexual or physical abuse in residential schools or through the foster care system, or because of the continued, day-to-day prejudice and segregation they continue to face because they are either Aboriginal, HIV positive, or they use illicit drugs. In this cycle of events, the only way to blockade one's psyche from reality was to partake in drugs ultimately leading to low adherence to HAART.

Other effects

Three respondents said historic trauma either did not affect their adherence to HAART and two others said that the experience of historic trauma helped them make the decision of choosing life over death, or made them stronger and smarter enough to be able to survive today's challenges in life. This therefore helped them stick to their medication.

It should be noted, however that, because some participants clearly state that they benefited from attending residential school (or from the child welfare system), this may be a statement to the remarkable ability of humans to create something positive even in the most oppressive conditions and their strong commitment to living a life based on justice and respect. It may not be a reflection of the value of these institutions.

Currently, the psychological situation in Aboriginal communities continues to have negative aspects and to be unhealthy and needs both redress and healing (Wesley-Esquimaux & Smolewski, 2004). It may be prudent to allow those who have experienced historic trauma freedom to participate in traditional ceremonies and other culturally-oriented practices so they can begin healing. This may be important in addressing the negative long-term psychological response and emotional impairment as well as maladaptive social and behavioural patterns, and may foster community development and cultural sustainability in the long run. Furthermore, stigma and discrimination may be particularly important to address, since they predispose individuals to repeated traumatisation (Wilson, 1989).

Medication-related Factors

Participants' responses reflected the fact that there is an association between medicationrelated factors and adherence to HAART (Kleeberger et al., 2001).

Complexity of Treatment

Many participants in this study indicated that, because of pill burden, fit to lifestyle and eating patterns, complete adherence was a daunting task. The main response was that decreasing the number of pills led to better adherence as it was much easier to take fewer pills. If someone was taking fewer pills the chances of medication interfering with ones daily activities may have been less. It is well known that the degree to which adherence to a regimen interferes with daily life is an important contributor to adherence and that, as the number of doses per day decreases adherence levels increase (Greenberg, 1984). Other respondents indicated that food requirements led to the difficulty to adhere to HAART since access to meals is not always at one's opportune time. One may not simply avoid a meal provided for him at a specific time in order to take a pill that is required to be taken on an empty stomach. Again, being too busy, as discussed before, may lead to simply forgetting to take a dose.

These results underscore the fact that, for therapeutic efficacy to be achieved, optimum levels of anti-retrovirals need to be maintained consistently to suppress HIV replication (Day, 2003). Although not indicated by respondents in this study, HIV/AIDS patients often suffer from co-morbid opportunistic infections because of their compromised immune system. Patients may therefore need to take more medication to treat these conditions (Altice et al., 2001). Additionally, the presence of other conditions, such as depression and drug and alcohol abuse, can compound the effects of regimen complexity on adherence (Ng et al., 200). Furthermore, when patients take too many medications they may report drug holidays as a result of pill fatigue.
Side effects

Medication side effects contributed in a significant way to the adherence to HAART for some of the respondents. This is consistent with studies that have shown that patients may be unable to maintain complete adherence because of development of side effects (Duran et al., 2001). This is always worrying because the effectiveness of HAART may be reduced because patients, because of fear of side effects, may not take their medication, as shown by one of the respondents.

Enough knowledge should be given to patients on HAART for them to be able to understand and accept possible side effects as one painful effect linked to the healing process. This understanding may help reduce possible internal conflicts and help the patient persevere or find ways to adhere better to treatment. It should be noted, however, that the value one attributes to HAART, HIV infection, and to life may determine interpretation of side effects. Providing the necessary information, with the aim that the patient understands what is happening when side effects occur and will seek medical assessment, is therefore vital.

Limitations

The purpose of this study is not to generalize the findings to a larger population, but to elicit the determinants of adherence to HAART in Aboriginal men in the DTES of Vancouver, and to provide recommendations for action that is culturally sensitive to the researched community. The results should help health personnel and members of the community ensure improved adherence to HAART informed by evidence.

There were a few limitations in this study. My life experience may have had an influence in the study. I have worked and lived among those affected by HIV/AIDS most of my life and have personal experience with close family members suffering from the disease. I, however, attempted to bracket my biases and preconceptions so that they did not influence the study. Throughout the study, I constantly wrote in a reflexive journal my thoughts and feelings. I reflected upon previous interviews, the day-to-day goings on, and the obstacles faced, drawbacks and successes.

To gain an in-depth understanding of the phenomena, the insights of these Aboriginal men were taken as truth of the men's stories. The information they provided may be limited as participants may have under-reported experiences due to being uncomfortable in sharing sensitive information or memories too painful to recall. I attempted to minimize this limitation through repeated assurances of confidentiality and through establishment of rapport with participants over time. However, the essence of people's beliefs and opinions on the determinants to adherence to HAART came out from this study.

The respondents in this study may have received different HAART combination regimens. It may be that some combinations are better tolerated and more likely to yield better longterm adherence and virologic suppression. The specific details, as to which of these combinations were perceived to cause more side effects and hence lead to decreased adherence to HAART, were not assessed as most patients just knew that they took three pills but could not recall the names.

This study utilized open-ended interviewing therefore the participants fully expressed their responses in as much detail as desired. This type of interviewing required a certain degree of expertise as an interviewer on my part. This was particularly challenging as I was working with a highly vulnerable population. My background as explained above was helpful in trying to manage and negotiate some of these difficulties. Furthermore, although the data provided by participants were rich and thick, it was a cumbersome process for me to sift through the responses in order to fully and accurately reflect an overall perspective of all interview responses through the coding process. In the focus group discussion, there were some dominant participants and some were extremely shy. This posed the danger of skewing the results. I therefore tried to redirect the course of the group or provided transition between questions in order to avoid dominance by some participants. This was not always easy.

It was not always possible to find a private and quiet environment in which to conduct the interviews despite making every effort. This may have made it difficult for some participants to talk in complete privacy thus impacting on the information provided. In addition, one interview was interrupted as one care provider came in to retrieve something. Two of the interviews had some inaudible data due to very loud background noise. I therefore had to relisten to the audio recordings to sift out the information when transcribing. I also verified the information with the participants later. Ultimately, a large amount of data was generated for analysis.

The recording device may have made the participants anxious or apprehensive, affecting their responses. However, the option of conducting the interview by just making field notes was given to all participants but they all consented for the interviews to be audio-recorded.

Most of the audio-recordings were transcribed by professional transcribers. On my part I had very little transcription experience and this could have affected the quality; however, the process of transcription is open to a range of human errors, including cultural differences and language errors (MacLean et al., 2004).

Finally, because of the nature of a master's study, the data were coded and themes identified in the data by only one person and the analysis then discussed with my supervisor. This process allowed for consistency in the method but failed to provide multiple perspectives from a variety of people with differing expertise.

Recommendation for Future Research

Based on the results of the study, there are several recommendations for future research. A high degree of expertise as an interviewer may be needed as such a study may be particularly challenging due to working with a highly vulnerable population and dealing with sensitive issues.

When using this method for another study, the coding of data could involve several individuals with themes' being developed using discussions with other researchers, and/or a panel of experts. By combining multiple researchers, substantial strides in overcoming the scepticism that greets lone analysts can be made.

This study could be replicated with Aboriginal youth participants. Different participants may yield different or similar results. Speaking directly to youth may help researchers see how generational effects of historic trauma are reflected. Youth are vulnerable but reluctant to speak about sensitive issues, but are currently participating in highly risky behaviours. Aboriginal youth not only tend to be at a greater risk of contracting the HIV virus, as they engage more in risky behaviours, they also currently have a higher rate of HIV cases than non-Aboriginal youth (PHAC, 2006).

Summary

This chapter has presented the discussion of the study. The chapter has been thematically organised with subheadings in line with those of results from both the dialogues and the focus group reflecting the story told in answer to the research aims and questions. The major topics covered have been patient factors, inter-personal factors, support structures, history of trauma/ residential school attendance (or child welfare system), and anti-retroviral medication factors as determinants to HAART adherence. Finally, the limitations of the study and recommendations for future research were presented.

Conclusion

This study explored the determinants of adherence to HAART in Aboriginal men in the DTES of Vancouver. The purpose was to elicit the determinants and offer recommendations to improve adherence and reduce deaths due to HIV/AIDS. The findings clearly demonstrate how challenging it is for HIV-positive patients to adhere to HAART.

The research method involved interviews and a focus group with those who were in a position to give their views and opinions, and tell their story on what affected their adherence to HAART. The Vancouver School of Doing Phenomenology methodology (Anderson, 2001) was utilized to elicit phenomena, including the nature of human lived experience from 22 participants.

Five main themes emerged from the analysis of the data obtained. Several procedures were used to examine the trustworthiness of the themes. The results indicate that adherence to HAART in Aboriginal men can be affected by; patient factors, inter-personal factors, support structures, history of trauma, and medication-related factors. Under the first theme, patient factors were depression, drug or alcohol abuse, the fear of either dying or having illness, procrastination, being too busy or just not caring, being unemployed, lacking faith and trust in care providers, and having episodes of memory loss adversely affected adherence to HAART. Being committed to taking medication and having a positive attitude to life, having stable housing, having adequate knowledge of drug resistance and interactions, and believing in ones traditional healing framework were associated with better adherence. Under the second theme, inter-personal factors; stigma and discrimination due to misunderstandings or lack of knowledge about HIV/AIDS, leads to fears of being treated with disdain, problems with confidentiality in small communities, not being wanted in one's own community or society, having a low sense of self-worth or low self-esteem, high degree of self-destructive

behaviour, including drug and alcohol abuse, and problems with confidentiality in small communities adversely affecting the number of people choosing to be on treatment when HIV-positive and lowering adherence to HAART. An open, respectful, understanding, and empathic patient-care provider relationship builds trust and fosters confidence in treatment regimens leading to better adherence. Under the third theme, support structures; the availability of a food program, support from care providers, fellow patients and friends, counselling services, methadone maintenance treatment, a medication pick-up and outreach, using traditional medicine, participating in learning circles and traditional ceremonies, and the availability of funding and services led to better adherence to HAART. Under the fourth theme, historic trauma; a history of trauma or residential school attendance, led to psychological and emotional pain, low self-esteem, self-blame, insecurity, fear, resentment, feelings of not being wanted/ accepted in society, a negative outlook on life, and substance abuse thereby reducing adherence to HAART. Historic trauma also led to development of survival skills, ultimately helping them adhere to their medication, and to some respondents making the decision to choose life over death. Finally, under the fifth theme, medicationrelated factors; decreasing the number of pills, and fitting medication regimen to food requirements and one's lifestyle, led to better adherence, whereas the development and fear of side effects to medication led to decreased adherence.

It should be noted, however, that in this study there is a web of plausible interlinked mechanisms or reasons why those who are on HAART may struggle to adhere to their medication. Even though the themes emanating from the respondents are distinct in their own right, the factors that affect adherence, as identified by the respondents cannot be seen in isolation. The implication of these inter-linkages is that, in order to manage the problem of low adherence one needs to look at the big picture, considering all factors together.

Because everything is connected to everything else, any aspect of our healing and development is related to all the others (personal, social, cultural, political, economic, etc.). When we work on any part, the whole circle is affected (Four Worlds, 1996).

The findings of this study contribute to the field of HIV/AIDS research by providing a reasonably comprehensive scheme of themes that describe, from the perspective of Aboriginal men living with HIV/AIDS, what affects their adherence to HAART. This study suggests promising developments in the determinants to HAART that have implications for both research and practice.

Implications for Practice

It may be prudent and worthwhile to consider the relationship between the experience of treatment, psychological distress, and other mental health issues, and to assess symptoms of depression closely in HIV patients with reduced adherence. This would enable clinicians diagnose depression early and provide appropriate treatment which may lead to enhanced adherence to HAART.

The first step in provision of care and treatment for alcohol and drug abusers should be the recognition of the existence of a community drug problem. This should be followed by development of targeted interventions. Enabling HIV-positive drug users to successfully utilize HAART requires attention to drug adherence. The key to effective HAART is careful assessment and education of the person leading to the development of an individualized treatment plan to maximize adherence.

Patients may need education on medication regimens (including possible interactions and side effects), development of drug resistance, and benefits of 100% adherence so they can adhere better to HAART.

The incorporation of, and an understanding of traditional beliefs and practices may be a good starting point for care providers as well as those seeking healing. Coupled with Aboriginal community-initiated programs and services, that reflect the needs of each community and facilitate empowerment for individuals, this could lead to better adherence to HAART.

Meaningful and adequately-paid employment opportunities for those living with HIV/AIDS should be made available so as to reduce the dependency on social service organizations for food, clothing, and other forms of assistance. This could fix the problem of adherence to HAART in the long run in this resource-poor setting of the DTES as more and more people experience stable livelihoods.

It is imperative that provision of safe and secure housing to patients on HAART should be considered a priority if adherence is to be improved.

Education of health care providers on Aboriginal history and culture may be imperative in the effort to reduce the impact of discrimination and promote better adherence to HAART. An increase in education about all health issues related to HIV/AIDS for people on the streets, and those on reserve, may be warranted if stigma and discrimination are to be reduced and adherence improved.

Systemic level barriers to adherence to HAART must continue to be challenged through activism from multiple forums (medical practitioners, counsellors, social workers, HIV activists and those living with HIV/AIDS).

Care providers need to remain engaged with their patients, assisting them with both social and psychological issues, in promoting better adherence to HAART. Maintaining an honest and open, patient- care provider relationship is critical to addressing adherence and its barriers. A better understanding of adherence and its determinants and how to define specific goals in the DTES clinical setting are keys for care providers to become more effective partners with patients in the achievement and maintenance of long-term virologic suppression and more importantly, long-term health (Conway, 2007).

Food assistance should be integrated into HIV treatment and prevention programs and each individual on HAART should be linked to a support mechanism that would ensure the availability of food at a convenient time on a daily basis.

Spirituality and transcendent ways of understanding the world need to be incorporated into modern ways if counselling is to be effective in meeting the needs of all Aboriginal clients. Any counsellor working in cross-cultural settings must always be aware of one's own cultural biases and assumptions (Sue & Sue, 1990).

There should be careful consideration of social and structural barriers that IDU face, coupled with a commitment to effect changes that foster conditions that enable IDU to adhere more to HAART. Integration of opiate addiction care and HIV care should be continued, and more outlets funded, in order to improve health outcomes for this vulnerable population.

The number of localised medication pick-up systems should be increased to help those on HAART in managing some problems they face in adhering to HAART. If possible, therapy should be dispensed at the site of overall patient care, allowing care providers maximum information about adherence and clinical response (WHO, 2004a).

Outreach strategies should be continued and intensified as they are a vital component of HIV care. They can help improve adherence to HAART and save lives. They can also provide an opportunity to form strong links with community-based organizations representing affected groups, and utilizing peer educators and counsellors drawn from these groups (WHO, 2004a).

Stable funding for more services and programs for those living with HIV/AIDS should be provided if adherence levels to HAART are to be improved. Medical care should be

accessible to the client and situated in facilities that are part of the general health care infrastructure, free-of-charge and user friendly with non-judgmental and unbiased staff. This care should also be comprehensive with the maximum possible number of the most needed services available at the one location (WHO, 2004a).

The medicine wheel approach should be considered and incorporated into current practice not only to improve adherence to HAART, but also to allow for medical pluralism and inclusivity. Furthermore, the attendance of teaching and sharing circles, and participation in ceremonies, of Aboriginal peoples should be encouraged in today's world if adherence to HAART is to improve.

The use of simple treatment options involving compact once-daily regimens should be made standard practice in order to increase adherence. This should be achievable with the increased availability of once-daily agents from a number of different drug classes that provide a wide range of treatment options. There should be a provision for adjusting medication schedules to the patient's meal or day to day program of activities. Furthermore, patients should be warned about potential side effects and the need to cope with them timely. Written information may need to be given to ensure patients co-operation and participation in the therapeutic process. All these implications for practice, aimed at achieving an ideal situation of 100 percent adherence, are summarised in Figure 1.

Finally, it is important, however, to note that while the determinants found here provide a rich understanding of the intricacies and complexities of adherence for these Aboriginal men on HAART, these findings are only a drop in the ocean. The results are only from patients drawn mainly from the VNHS, an HIV/AIDS care program in the DTES of Vancouver. Other types of patients (e.g., the youth or individuals who live on reserve) may have different determinants. This possibility may need to be researched in the future.



Figure 1. Summary of Implications for Practice

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7.0 APPENDICES

Appendix A

UNBC REB Ethics Approval Letter

UNIVERSITY OF NORTHERN BRITISH COLUMBIA

RESEARCH ETHICS BOARD

MEMORANDUM

- To: Meck Chongo
- CC: Mamdouh Shubair
- From: Henry Harder, Chair Research Ethics Board
- Date: October 5, 2010

E2010.0920.132 An Investigation of the Determinants of Adherence to Highly Active Anti-Retroviral Therapy in Aboriginal Men in the Downtown Eastside of Vancouver

Thank you for submitting the above-noted research proposal to the Research Ethics Board. Your proposal has been approved.

We are pleased to issue approval for the above named study for a period of 12 months from the date of this letter. Continuation beyond that date will require further review and renewal of REB approval. Any changes or amendments to the protocol or consent form must be approved by the Research Ethics Board.

Good luck with your research.

Sincerely,

Henry Harder

Appendix B

VNHS Support Letter



Vancouver Native Health Society

Positive Outlook Program

Research Review Committee UNBC - Office of Research 3333 University Way Prince George, BC V2N 4Z9

25th August, 2010

Ref: Proposal titled "An investigation of the determinants of adherence to highly active antiretroviral therapy in Aboriginal men in the Downtown Eastside of Vancouver".

Dear Research Review Committee:

The Vancouver Native Health Society (VNHS) is pleased to provide a letter of support for Meck Chongo's study of the determinants of adherence to highly active antiretroviral therapy in Aboriginal men in the Downtown Eastside of Vancouver.

According to our VNHS clinic reports (2008/2009), the number of HIV-positive Aboriginal patients served has increased but only around 33% of patients are on Highly Active Antiretroviral Therapy (HAART), with males being less likely than females to access treatment. The mortality rate, for the Aboriginal population, has more than doubled, with 26 of the 57 deaths in 2008 alone being Aboriginal (VNHS, 2008/2009). A key factor contributing to these deaths is the problem of sub-optimal adherence to HAART. Recently, the BC Health Ministry marked World AIDS Day by delivering severe funding cuts to HIV/AIDS service directed Community Based Health Organizations (CBHO's). Now, given that 18% of Canada's estimated total HIV-positive population lives in BC, and that BC represents approximately 13% of the overall population of Canada; BC has a disproportionate share of the HIV burden.

We have had, and continue to have, obvious positive outcomes for those serviced by the VNHS clinic. There however has not been any investigation/ critical examination of factors that determine adherence to HAART and how these interact. We believe the study is important to Aboriginal communities because, if the voices of men in particular, priority areas for policy and resources, and potential targets for intervention, can be identified. Incorporating history into awareness programs, and using culturally-sensitive interventions that address these determinant factors, may help to reduce deaths due to HIV/AIDS by improving adherence to HAART. The results from this thesis/ research will also help argue for more funding or a reversal of funding cuts. We would therefore be happy to be part of this study and provide support to this important work.

441 E. Hastings Street, Vancouver, BC, V6A 1P5 PH: 604-254-9937 Fax: 604-254-9948

Yours sincerely,

Lou bemeraig ----Executive Director Vancouver Native Health Society 449 East Hastings Vancouver BC V6A 1P5

<u>vnhs@shawbiz.ca</u>

Phone: 604.254.9949 Fax: 604.254.9948 http://www.ynhs.net

441 E. Hastings Street, Vancouver, BC, V6A 1P5 PH 604-254-9937 Fax 604-254-9948

Appendix C

Participant Information Form



Patient Participant Information Sheet

PROJECT TITLE: An Investigation of the Determinants of Adherence to Highly Active Anti-Retroviral Therapy in Aboriginal Men in the Downtown Eastside of Vancouver.

PRINCIPAL INVESTIGATOR: Meck Chongo, Community Health Sciences, University of Northern British Columbia.

PURPOSE OF THE STUDY: The purpose of this study is to investigate the determinants of adherence to highly active anti-retroviral therapy (HAART) in Aboriginal men in the Downtown Eastside (DTES) of Vancouver. This work and the anonymous information collected will be used by the principal investigator, Meck Chongo, as part of his Master's thesis, as well as to offer culturally-sensitive recommendations to decision-makers on how to better address the effects of the determinants and/ or unresolved pain, aimed at improving access to HAART among Aboriginal men and reducing deaths due to HIV/AIDS.

WHAT DO YOU WANT FROM ME? You are being invited to participate in this study because you live in the DTES of Vancouver in British Columbia (BC), you are more than 25 years of age, you are currently, or have previously been, on HAART, you are able to communicate in English, and you either attend and/ or are serviced by the Vancouver Native Health Society (VNHS) clinic. We would like to talk to you, at a place that is convenient for you to tell us about your HAART and health care experiences. This should take about 45-60 minutes of your time.

VOLUNTARY PARTICIPATION: Taking part in the study is voluntary.

COMPENSATION: After we complete the interview we would like to provide you with \$20 in appreciation of your time.

CONFIDENTIALITY: The information collected during the interview will be kept private and confidential. Your name will not appear anywhere. Taking part in this interview will not affect your health care in any way. If you have any questions about the study or would like to arrange an interview, please do not hesitate to call Meck Chongo (250) 981-5161. You may also call Dr. Mamdouh Shubair, Assistant Professor at the UNBC at (250) 960-6331. Appendix D

Consent Form



THE UNIVERSITY OF NORTHERN BRITISH COLUMBIA

Department of Community Health Sciences

3333 University Way, Prince George, BC V2N 4Z9 Tel: (250) 960-5363 Fax: (250) 960-5744 Website: <u>www.unbc.ca</u>

Informed Consent Form for Participants

"An Investigation of the Determinants of Adherence to Highly Active Anti-Retroviral Therapy in Aboriginal Men in the Downtown Eastside of Vancouver"

Research Supervisor:

Mamdouh Shubair, PhD Assistant Professor Program Health Sciences Programs Phone: (250) 960-6331 Fax: (250) 960-5744 Email: <u>shubair@unbc.ca</u> **Principal Investigator:**

Meck Chongo, MBChB Community Health Sciences

Email: chongo@unbc.ca

You are being asked to participate in this study because we are interested in hearing about your experiences with seeking and/ or receiving highly active anti-retroviral therapy (HAART). You will be encouraged to provide examples of experiences that highlight both your challenges and successes in adhering to HAART. I am conducting this study in Vancouver, BC. By participating in this interview, you have the opportunity to tell your story. You may take your time to make your decision about participating in this study and you may discuss it with your friends or family before you make your decision. This consent form may contain words that you do not understand. Please feel free to ask us to explain any words or information that you do not clearly understand.

Study Purpose: The purpose of this study is to investigate the determinants of adherence to highly active anti-retroviral therapy (HAART) in Aboriginal men in the Downtown Eastside (DTES) of Vancouver. This work and the anonymous information collected will be used by

the principal investigator, Meck Chongo, as part of his Master's thesis, as well as to offer culturally-sensitive recommendations to decision-makers on how to better address the effects of the determinants and/ or unresolved pain, aimed at improving access to HAART among Aboriginal men and reducing deaths due to HIV/AIDS.

Study Methods: Your participation in this study will involve taking part in a 45-60 minute interview and/ or focus group discussion. Each interview/ focus group will be audio-taped. You will be asked about your experiences with seeking and/ or receiving antiretroviral treatment, as well as some information about your age, education, and where you live. Your participation in this study is entirely voluntary. The decision to participate (or not) is totally up to you. You may choose at any time not to answer a question, change your responses, withdraw an answer, or stop the interview. Refusal or withdrawal from the study will in no way affect any treatment, clinical care, or support that you are currently receiving.

Risks and Benefits: You personally may not receive any direct benefits from taking part in this study, but no risks are expected from participating. However, due to the sensitive nature of this topic, you may experience uncomfortable feelings or memories. Should this happen, the interview will be terminated and you will be referred to a qualified counsellor (from within the VNHS) for assistance. Your answers will help me give recommendations to better address the effects of the determinants and/ or unresolved pain, aimed at improving access to HAART among Aboriginal men and reducing deaths due to HIV/AIDS.

Payment for Participation. At the end of the interview (or if the interview is terminated prematurely) and/ or focus group discussion, I would like to give you \$20 in appreciation of your time and participation in this study.

Confidentiality: Information collected in this study is strictly confidential. Your identity will be kept strictly confidential. We will not release your name to anyone. Audio-tapes will be transcribed, anonymized, and securely locked in a filing cabinet at UNBC and computer files will be password protected. Your participation in this study may be used for the purposes of presentations and/or publications resulting from this study. No names or other unique identifiers will be included in the transcripts or used in any published report.

"Your rights to privacy are also protected by the Freedom of Information and Protection of Privacy Act of British Columbia. Further details about this Act are available upon request." (Freedom of Information and Protection of Privacy Act of British Columbia)

Storage of Data: Tape recordings will be securely locked in a filing cabinet and kept for two years at UNBC after the study is completed and then the cassette tapes will be destroyed. Interview transcripts, names, and contact information will be kept for three years after the completion of the study at which time the documents will be shredded and the electronic file deleted.

For More Information: If you have any questions or desire further information during or after the study, please contact the principal investigator or research supervisor at the phone numbers listed above. If you have any concerns about your treatment or rights as a research subject, please contact the Office of Research in the UNBC at (250) 960 5650 or reb@unbc.ca.

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions. By signing this consent form, you are agreeing to take part in this study, and acknowledge receipt of a copy of this consent form for your records.

Statement of Consent

To be completed by the Research Participant (Circle either YES or NC))	
Do you understand that you have been asked to be in a research study?	YES	NO
Have you read and received a copy of the attached information sheet?	YES	NO
Do you understand that some of you actual words may be published in a written form?	YES	NO
Do you understand the benefits and risks of the study?	YES	NO
Do you know what resources you can access for supportive counseling?	YES	NO
Have you had the opportunity to ask questions and discuss this study?	YES	NO
Do you understand that you are free to refuse to participate or to withdraw from the study at any time?	YES	NO
Has the issue of confidentiality been explained to you?	YES	NO

Do you understand who will have access to the information you	YES	NO
provide?		
Do you have any further questions?	YES	NO

I consent to be involved in the following study procedures: (Check all that apply)

- □ Interview
- □ Focus Group

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

Printed Name:	Date:
Signature:	

Principle Investigator

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believed that the participant has understood and has knowingly given their consent.

Printed Name:	Date:

Signature:

Role in the Study: _____

Would you like to receive a written summary of results of the study?

□ Yes □ No

If yes, please write down your contact information

Name:

Address:

Phone number:

Email:

Appendix E

Interview Guide



INTERVIEW QUESTIONS:

- 1. How are you?
- Please, tell me a bit about yourself.
- 2. Where are you from?
- 3. How do you identify your heritage/ from where do you trace your origin?
- 4. How old are you now?
- 5. Where do you live?
- How long have you lived there?
- Is this a temporary place?
- 6. What do you do for a living? Are you a stay home parent?
- If you work, where and what is your average yearly income?
- 7. How would you define the word 'health'?
- What does good health or alternatively poor health look like?
- 8. How would you describe your health right now?
- 9. Tell me how you first found out about the VNHS clinic.
- How long have you been coming here or using the services of VNHS?
- What brought you here in the first place?
- What was your experience like when you first came here?
- 10. What kinds of things do you come here for?

- What kinds of things/ activities are you involved in here? How is that going?
- What keeps you coming back to this clinic?
- 11. What is important to you about the care/ services provided at this clinic?
 - What is it that you rely on most from this clinic?
 - Can you give me an example?
- 12. Did you get the help you needed with respect to HIV-related health services?
 - If yes, tell me more about that.
 - If not, why do you think you didn't get the help you needed?
 - Do you feel you may need to move, or have you already moved, to be closer to HIV-related health services?

13. How has the HIV-related care/ services you received here affected your health or wellbeing?

- Can you give me an example?
- 14. What is your experience with/ how long have you been on HAART/ARVs?
- 15. What ARV medications are you taking? How do you take them?
 - Have you missed any of the medication recently? How many? When?
 - What are the reasons that may have caused you to miss your medications/ what gets in the way of you taking HAART/ARVs?
- 16. How are you managing to take your medication/ what helps you take your medications?

17. Do you face any problems adhering/ sticking to treatment?

- If yes, tell me more about that.
- Is this a one off or does it happen often?

18. What influences or affects your ability to take your medication/ ARVs?

19. How has being diagnosed with HIV/AIDS affected your relationship with your doctor/care providers?

- Has this changed your trust in your doctor/care providers? If so, in what way?

- What was the same or different in your relationships with your caregivers after your diagnosis?

20. Do you have an image of HIV/AIDS, or how would you describe HIV/AIDS?

- What feelings come to mind?
- What meaning does it have in your life?

21. What is your experience with HIV/AIDS (since diagnosis)? What do you think about HAART/ARVs?

- Did you attend a Residential School? If yes, for how long?
- Did your parents, guardians or grandparents attend a Residential School?
- Do you believe that this Residential School experience has affected your health?
- How or why has it affected your health?

22. I am also interested in knowing if the clinic has helped you get other kinds of services. For example, have you been helped with/ referred to:

- Organizations offering traditional Aboriginal healing practices?
- Have these been useful to your treatment? If so, why?
- 23. Have you had any problem making appointments? If so, why?
 - Can you give me an example?
 - Any barriers you have faced?
 - Any attitude/ stigma/ prejudice problems?
- 24. What are some of the reasons why the HAART/ARV service might not meet your needs?
- 25. What is the best way that treatment services can be improved for you?
 - How could services meet your needs?
 - What is missing?

26. Do you have any other comments about your HIV/AIDS care, treatment or support services?

Appendix F

Focus Group Guide



FOCUS GROUP QUESTIONS:

- 1. Tell me how you first found out about the VNHS clinic.
- 2. How would you define the word 'health'?
- 3. What kinds of things do you come here for?
- 4. What is important to you about the care/ services provided at this clinic?
- 5. How has the HIV-related care/ services you receive affected your health or well-being?
- 6. What do you think about HAART/ARVs?
- 8. How are you managing to take your medication/ what helps you take your medications?
- 9. Do you face any problems getting and sticking to treatment?
- 10. What things/ circumstances may cause one to miss their medications?

11. How has being diagnosed with HIV/AIDS affected your relationship with/ trust for your doctor/ care providers?

- 12. What feelings come to mind when you think of HIV/AIDS?
- 13. Do you believe that the experience of Residential School affects one's health today?
- 14. What other kinds of services has the clinic helped you get?
- 15. Have you had any problem making appointments at the clinic? If so, why?
- 16. What are the reasons why the HAART/ARV service might not meet your needs?
- 17. What is the best way that treatment services can be improved for you?

18. Do you have any other comments about your HIV/AIDS care, treatment/ support services?

19. Any questions about the research?

Appendix G

Participant Contact Form

"An Investigation of the Determinants of Adherence to Highly Active Anti-Retroviral Therapy in Aboriginal Men in the Downtown Eastside of Vancouver"

Supported by: University of Northern British Columbia (UNBC) and Vancouver Native Health Society (VNHS).

If you are interested in participating please list your contact information below. A member of the Group Medical Visits research team will contact you to talk about participating in this research project. The information you provide here will not be shared with any third parties and will only be used to contact you in regards to this study

Name:
Phone number (home):
Phone number (cell):
Phone number (work):
Email:
Address:
Address 2:
City:
Postal Code:

Appendix H

Demographic Information Sheet

Please circle or tick the applicable choice or answer the question on the line provided.

Current Age: _____

Age when diagnosed with HIV/AIDS:

Age when treatment for HIV/AIDS started:

Current number of HIV medications:

Types of service providers you saw in the past 12 months (check all that apply):

Family Doctor:	
Ophthalmologist:	
Hospital Emergency Department:	
Mental Health Counsellor:	
Dietician:	
Social Worker:	
Nurse:	
Other: Specify	

Current Marital Status:

Single Married Co-Habiting Divorced Widowed Separated
Employment Status: Full-time Part-time Unemployed Student
Employed Seasonally Permanently out of the workforce due to disability/illness
Permanently out of workforce due to being a work at home parent
Level of Education Achieved:
Elementary School Some High School High School Some University/College
College Diploma Undergraduate Degree Graduate Degree Other
Current Housing:
Own house Rent house BC housing Temp hotel room No fixed aboard/street
Other Specify

Appendix I

Transcriber Confidentiality Form



Transcriber Confidentiality Agreement

This study has been reviewed and approved by the Research Ethics Board of the University of Northern British Columbia and the Ethics Board of the Vancouver Native Health Society. The purpose of this study is to investigate the determinants of adherence to highly active anti-retroviral therapy (HAART) in Aboriginal men in the Downtown Eastside (DTES) of Vancouver. This work and the anonymous information collected will be used by the principal investigator, Meck Chongo, as part of his Master's thesis, as well as to offer culturally-sensitive recommendations to decision-makers on how to better address the effects of the determinants aimed at improving access to HAART among Aboriginal men and reducing deaths due to HIV/AIDS. A final report on the research will be presented to the University of Northern British Columbia, and the results may be written up for publication or conference presentations.

Thesis Title: An Investigation of the Determinants of Adherence to Highly Active Anti-Retroviral Therapy in Aboriginal Men in the Downtown Eastside of Vancouver.

- I, _____, the Research Transcriber, agree to:
- 1. keep all the research information shared with me confidential by not discussing or sharing the research information in any form or format with anyone other than the *Principal Investigator*.
- 2. keep all research information in any form or format secure while it is in my possession.
- 3. return all research information in any form or format to the *Principal Investigator* when I have completed the research tasks.

4. after consulting with the *Principal Investigator*, erase or destroy all research information in any form or format regarding this research project that is not returnable to the *Principal Investigator* (e.g., information stored on computer hard drive).

Research Transcriber			
Name	Signature	Date	
Principal Investigat	or		
Name	Signature	Date	

If you have any questions or concerns about this study please contact Meck Chongo on <u>chongo@unbc.ca</u>. Any complaints about the study can be directed to the Office of Research, UNBC at 250-960-5820 or <u>www.unbc.ca/research/</u>.

Appendix J

Group Agreement for Maintaining Confidentiality

This form is intended to further ensure confidentiality of data obtained during the course of the study entitled "An Investigation of the Determinants of Adherence to Highly Active Anti-Retroviral Therapy in Aboriginal Men in the Downtown Eastside of Vancouver". All parties involved in this research, including all focus group members, will be asked to read the following statement and sign their names indicating that they agree to comply.

I hereby affirm that I will not communicate or in any manner disclose publicly information discussed during the course of this focus group interview. I agree not to talk about material relating to this study or interview with anyone outside my fellow focus group members and the researcher (or moderator).

Moderator's signature:	<u> </u>
Name:	Signature:
Name:	Signature: