

**ACCESSING HAART IN NORTHERN BC: UNDERSTANDING THE BARRIERS AND
SUPPORTS TO MEDICATION ADHERENCE AND ENGAGEMENT IN HIV-
RELATED CARE**

By

Michael David Jordan

B.Sc., University of Victoria, 2006

B.A., University of Victoria, 2010

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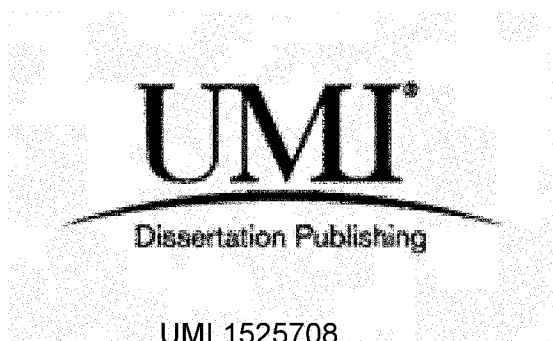
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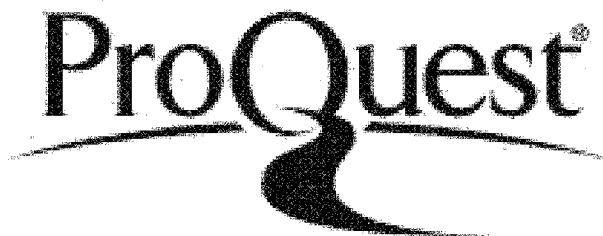


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Abstract

Highly active antiretroviral therapy (HAART) has significantly improved the health and well-being of many people living with HIV. Successful treatment with HAART requires a very high level of adherence, and continued engagement with health care services. Particular challenges to successful treatment with HAART exist in northern BC, but little research has been done in this region. This study investigated the experiences of those prescribed HAART who live in northern BC in order to identify what barriers and supports exist to optimal adherence, and engagement in HIV-related care. In-depth interviews indicated the complex and intersecting factors which affect adherence and engagement in care. Proximal, intermediate and distal social determinants of health which are relevant to adherence and engagement in HIV-related care were identified. Depression and stress, prioritization, and access to medications and care were identified as mechanisms in which various factors acted as barriers to adherence and engagement in care.

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Glossary of Acronyms

AIDS	Acquired Immunodeficiency Syndrome
ARV	Antiretroviral
BCCfE	British Columbia Centre for Excellence in HIV/AIDS
CBAO	Community-based AIDS Organization
DTP	Drug Treatment Program
DOT	Directly Observed Therapy
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
MASP	Medication Adherence Support Program
MMT	Methadone Maintenance Therapy

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Chapter 1: Introduction

Rationale for research project

Highly active antiretroviral therapy (HAART) has dramatically changed the course of HIV infection and many living with HIV can now expect close to normal life expectancies (Hogg et al., 2013). HAART has been shown to significantly decrease morbidity and mortality due to HIV. In British Columbia, HAART is available free of charge to people living with HIV who meet certain eligibility criteria¹ (Montaner et al., 2010). Increasing the proportion of people living with HIV who are receiving HAART within a population has also been shown to decrease HIV transmission rates, and can be viewed as both a treatment and prevention for HIV infection (Montaner et al., 2010). The benefits of HAART are clear at the individual and population levels. However, while HAART has improved over the years by reduced pill burden and associated increased tolerability for patients, problems remain including difficulties in expanding access to HAART, challenges for individuals in maintaining treatment at the recommended level of adherence, and the development of resistance to available drugs (Montaner et al., 2010). Not all of those living with HIV in British Columbia are experiencing the benefits of HAART. The British Columbian Northern Interior and Northwest health service delivery areas (HSDA),² report rates of HIV infection which are among the highest in the province (BCCDC, 2010). The Northern Health Authority is the only health authority in British Columbia (BC) with increasing rates of HIV-related mortality (Lima et al., 2010).

¹ Initiation of antiretroviral therapy is recommended if CD4 cell count is less than 500/ μ L or if patient is symptomatic, and should be considered when asymptomatic and CD4 cell count is greater than 500/ μ L (BC-CfE, 2010).

² Northern British Columbia is split into 3 health service delivery areas (HSDA): Northwest, Northern Interior and Northeast.

For treatment with HAART to be successful (defined as an undetectable viral load³) a high level of adherence (95%) to therapy is necessary (Castro, 2005). Treatment with HAART also requires regular monitoring of CD4 cell counts and HIV-1 plasma viral loads to ensure treatment effectiveness, and to detect early the development of antiretroviral (ARV) resistance which signals the need for changing the particular drug regimen comprising HAART (Thompson et al., 2010). Engagement with primary and specialist care is also important to the quality of HIV-related health care (Gardner et al., 2011). Achieving treatment success can be a challenge for many who are eligible for this treatment. A better understanding of peoples' experiences with HAART in two different communities will provide information which could be used to improve HIV treatment and care in northern BC.

Given these challenges, the purpose of this study was to investigate peoples' experience of being on HAART and to identify the barriers and supports to adherence to HAART and engagement in HIV-related care in Prince George (located within the Northern Interior HSDA), and Smithers (located in the Northwest HSDA) in order to inform ways of improving HIV care and treatment outcomes in northern BC. Few studies have investigated peoples' experience with HAART in northern BC, and to my knowledge no studies have taken place in rural areas of northern BC outside of the city of Prince George. The principal research question is what are the barriers and supports to adherence to HAART and engagement in HIV-related care experienced by people who have been prescribed HAART within these two northern BC communities.

I have chosen to take on this research topic for several reasons. First, my experience as a volunteer with different Community-based AIDS organizations in Canada and internationally

³ An undetectable plasma viral load is defined as being under 40 copies HIV-1 RNA per millilitre blood plasma.

allowed me to get to know people living with HIV and to learn about some of the challenges they face. With HAART being one of the most promising developments in HIV care and treatment, ensuring access for everyone who needs HAART is an issue of social justice. Having grown up in northern BC, I wanted to focus my research within this region in part because of my personal connection to the area. My decision to focus on this research topic was also influenced by the evidence of significant barriers to HIV treatment in northern BC as well as the fact that little research on this topic had been done in this region. Ultimately, my hope is that by focusing on participants' experiences with HAART there is potential for the research findings to have an impact on improving the quality of HIV care in this region.

This thesis is organized into six chapters. Chapter 2 provides background information related to HAART, an overview of the HIV epidemic in northern BC, and discussion on some commonly identified barriers and supports related to treatment with HAART. Chapter 3 discusses the methodology used for this research. Chapter 4 presents the results of this research. Chapter 5 is a discussion of these results with reference to relevant academic literature. Chapter 6 concludes this thesis with a review of the relevant findings, suggestions for future research, and recommendations for improving HIV treatment outcomes in northern BC.

Chapter 2: Review of Literature

The purpose of this research was to investigate peoples' experience of being on HAART and to identify the barriers and supports to adherence to HAART and engagement in HIV-related care experienced by those living with HIV in northern BC, in order to inform ways to improve HIV care and treatment outcomes in this region. This literature review utilizes available evidence to address some of the potential barriers and supports to adherence to HAART and engagement in HIV-related care in northern BC. First, background information on HAART and the epidemiology of HIV in northern BC is given. Next, I will discuss how HAART is delivered within British Columbia and best practices for treatment. Research on barriers and supports to adherence to HAART will then be reviewed. Searches of electronic databases including Medline, CINAHL, PubMed and EBSCOhost were performed to retrieve relevant articles. Also, relevant articles were found through the publications page of the British Columbia Centre for Excellence in HIV/AIDS, and from the Public Library of Science.

Background on HAART

HAART is seen as the major success in HIV and AIDS treatment while efforts towards the development of a vaccine and cure have yet to be successful (Montaner et al., 2010). Evidence has shown that a 20 year old HIV positive individual on HAART in the United States or Canada can expect to live in to his or her early 70s, but there exist significant disparities in life expectancies (Hogg et al., 2013).

HAART is a combination of drugs which act by reducing the rate of HIV replication, thereby allowing recovery and minimizing damage to the immune system (Montaner et al., 2010). The use of a combination of drugs, each inhibiting a different mechanism of viral

replication, slows the development of antiretroviral drug resistance (Castro, 2005). The drugs used in HAART are categorized into classes on the basis of the viral replication mechanism they inhibit (Castro, 2005).

Delivery of HAART in British Columbia

The British Columbia Centre for Excellence in HIV/AIDS (BC-CfE) Drug Treatment Program (DTP) is mandated by the provincial government to provide free anti-HIV medication to all eligible residents in BC (Vasarhelyi et al., 2011). Eligibility is determined by the therapeutic guidelines committee at the BC-CfE (BC-CfE, 2011). The increased effectiveness and tolerability of HAART, and evidence showing increased risks with untreated HIV infection have led to the expansion of eligibility criteria for HAART (BC-CfE, 2010). The process for beginning HAART starts with a physician enrolling a patient in the DTP (BC-CfE, 2011). The physician prescribing anti-HIV drugs to a patient for the first time will send an HIV/AIDS drug request prescription form to the DTP, the patient will then be enrolled in the DTP, the prescription will be checked and then approved by the BC-CfE and the drugs then are sent to a specified location for patient pick up (BC-CfE, 2011). As of January 2011 there were 147 patients enrolled in the DTP within the Northern Health Authority (BC-CfE, 2011).

Adherence to HAART

Adherence to the prescribed ARV regimen is one of the most important factors to successful treatment (Castro, 2005). Adherence, sometimes called compliance, refers to how closely patients follow prescribed treatment regimes. A high level of adherence (95%) is necessary to avoid the development of ARV resistance (Racey et al., 2010). The development of resistance is a problem because fewer anti-HIV drugs are then available for treatment, and resistance to

certain drug classes has been associated with a higher risk of death (Racey et al., 2010). ARV resistant HIV infection can also be transmitted, thereby making resistance testing prior to beginning HAART important (Eyawo et al., 2011). There must be caution in any discourse related to adherence to HAART. Problems arise when individuals are blamed for non-adherence without consideration of factors which make adherence particularly challenging. Many different factors are associated with adherence and high levels of adherence to HAART should not be considered solely the responsibility of the individual. This idea is shared by Krüsi (2010) and colleagues who wrote the following:

We propose a conceptual shift away from understanding suboptimal HAART adherence as determined predominantly by individual factors modifiable through individually focused interventions, towards a greater acknowledgement of the influence of social and structural factors such as stigmatization and social exclusion, unstable housing environments, the organization of health care systems and the continued prohibitionist approach to illicit drug policy (Krüsi, et al., 2010, p. 4)

While individual factors affect adherence to HAART, such as mental health or substance use, these factors are affected by social contexts.

Best practices for HAART

While a high level of adherence is an integral component to the success of treatment with HAART it is not the only relevant factor. Best practices for treatment with HAART are described in therapeutic and primary care guidelines distributed by the BC-CfE (BC-CfE, 2010). Therapeutic guidelines consist of prescription guidelines as well as guidelines for monitoring treatment. Many variables exist for the choice of treatment regimens and the BC-CfE guidelines recommends that “the initial regimen should be individualized according to resistance testing

results and predicted antiviral efficacy, toxicity and tolerability, pill burden, dosing frequency, drug-drug interactions, co-morbidities, and patient and practitioner preference” (BC-CfE, 2010, p. 7). It is recommended that drug resistance testing is done prior to beginning treatment to ensure drugs prescribed will be effective. However, research in BC has shown that drug resistance testing is not being done as recommended by the BC-CfE therapeutic guidelines and lower rates of resistance testing is seen for Aboriginal patients and women (Eyawo et al., 2011). Monitoring of treatment success by measuring HIV viral load and CD4 cell counts should take place every 3 to 4 months, and more frequently when HAART is first initiated (Thompson et al., 2010). This level of monitoring requires a high level of engagement with health care services, and creates potential challenges for people on HAART in rural areas who need to travel to access care. While treatment itself is free, there may be associated costs to receiving treatment and related health care. Also, the potential fear of being “outed” as HIV positive in communities where stigma towards people living with HIV is high may be another barrier to the regular engagement in HIV-related care. The various challenges faced by people living with HIV in receiving the optimal level of care and achieving optimal adherence to HAART is acknowledged in the BC-CfE therapeutic guidelines in the concluding statement of the document.

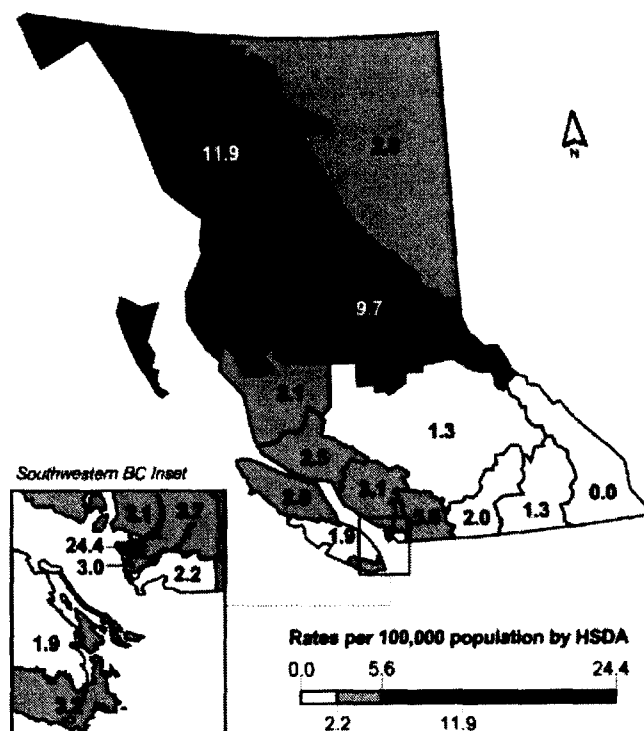
One of the greatest remaining challenges is that full implementation of these guidelines will require addressing social and structural barriers to diagnosis and care, particularly to the most affected population including: men who have sex with men, drug users, sex trade workers, and Aboriginal individuals. Additionally, it is imperative that the pervasive stigma and discrimination towards infected and at-risk populations be urgently addressed (BC-CfE, 2010, p. 27).

The high level of adherence necessary for HAART to be successful, coupled with the ongoing engagement with health care services, makes being on HAART a potentially onerous prospect. As the above quote points out, those who face greater social and structural barriers to care are at a greater risk of not achieving the full benefit of being on HAART.

Epidemiology of HIV in northern British Columbia

An understanding of some of the basic epidemiological measures of the HIV epidemic within northern BC can shed some light on the HIV care needs of this region. The HIV epidemic in northern BC differs from the larger scale HIV epidemic taking place in the south of BC in a number of ways.

Figure 1. HIV infection rates in 2011 by health service delivery area in BC (BC CDC, 2012)



In 2011 rates of infection of HIV were high in the Northwest and Northern Interior HSDAs at 11.9 and 9.7 new positive tests per 100,000 , but low in the North East HSDA at 2.8 new positive tests per 100,000 (BCCDC, 2012). The rates of new HIV infection in 2011 for all of the HSDAs in BC are shown in figure 1. The provincial average rate of new infections was 6.3 per 100,000 in 2011, and the HSDA with the highest rate of infection was Vancouver with a rate of 24.4 per 100,000 (BCCDC, 2012). While the rates are high in northern British Columbia, it must be acknowledged that because of the small population in these regions these rates relate to 9, 14 and 2 total new cases in 2011 for the Northwest, Northern Interior and North East HSDAs respectively (BCCDC, 2012). Within the Northwest and Northern Interior HSDAs the cumulative number of persons newly testing positive for HIV between 1995 and 2008 is 59 and 154 respectively (BCCDC, 2008). Between 1989 and 2009 there were 323 people newly diagnosed within the Northern Health Authority, and since 2003, when HIV became a reportable disease, there have typically been over 20 people newly diagnosed per year (Northern Health, 2010). Within the Northern Health Authority there were 16 new HIV positive tests in 2010, and 24 new positive tests in 2011 (Northern Health, 2012). These numbers represent only those who have newly tested HIV positive within the Northern Health Authority, which is not a direct representation of new HIV infections as it is estimated that about 26% of HIV positive individuals in BC are unaware of their status, and people may test positive in another health authority prior to residing in northern BC (Northern Health, 2010).

Another important measure of an HIV epidemic is the mode of viral transmission. In 2011 there were 24 newly identified HIV infections within the Northern Health Authority (Northern Health, 2012). The identified risk factor for transmission in 11 cases (46%) was injection drug use, in 8 cases (24%) heterosexual intercourse, 3 (12.5%) did not identify any risk

factor or the risk factor was unknown, and in 3 (12.5%) the risk factor identified was men who have sex with men. Province-wide data on new HIV infections by exposure category in 2011 shows men who have sex with men as the most affected population comprising 57.8% of new infections, followed by heterosexual exposure (24.6%) and injection drug use (12.1%) (BCCDC, 2011). The HIV epidemic in northern British Columbia is largely driven by injection drug use, followed by heterosexual intercourse. Some caution should be taken in interpreting this data, as some risk factors for HIV infection may be more stigmatized than others, and therefore may be underreported.

In a 2008 survey of injection drug users in Prince George, it was reported that 41% had lived in another city or town in northern BC within the last 6 months, indicating a high level of mobility which creates a barrier to the continuity of health care (Callaghan, 2009). People who are living with HIV within northern BC may leave home communities in search of better treatment services, or because of fear or effects of stigma associated with HIV status, or injection drug use. It may also be that people living with HIV return to home communities in northern BC to seek supportive care from family and their community. A better understanding of the reasons affecting the decisions of people living with HIV to move between communities is important to understanding where services are lacking or problematic.

Of the newly reported HIV infections in 2009 in the Northern Health Authority, 16 (59%) were men and 11 (41%) were women (Northern Health, 2010). This data shows a higher proportion of infections in women compared to provincial data where women comprised only 21% of newly reported infections in 2009 (BCCDC, 2010). Also, women within the Northern Health Authority were reported to have HIV viral loads 3 times higher than men, indicating

barriers to treatment may be particularly significant for women in this region (Ministry of Healthy Living and Sport, 2007).

An over-representation of Aboriginal peoples in HIV infection rates is seen in the Northwest and Northern Interior HSDAs (Northern Health, 2009). Between 2007 and 2009 16 people who identified as Aboriginal newly tested HIV positive in the Northwest HSDA compared to 10 people testing newly positive who did not identify as being Aboriginal (Northern Health, 2010). Also, between 2007 and 2009, 30 people who identified as being Aboriginal newly tested positive for HIV in the Northern Interior HSDA compared to 13 people who did not identify as being Aboriginal (Northern Health, 2010). These findings require the acknowledgment of the impact of colonization including the “forced removal from traditional lands, economic deprivation, cultural genocide and in particular histories of the residential school and child welfare systems” (Mehrabadi et al., 2008, p. 237). Reading & Wien (2009) also link the past and present influence of colonialism on Aboriginal people.

While neo-colonialism detrimentally influences the health of contemporary Aboriginal peoples, historic, successively traumatic events continue to affect generations through what has been referred to as ‘historic or cultural trauma.’ In essence, the collective burden of a repressive colonial system has created conditions of physical, psychological, economic and political disadvantage for Aboriginal peoples. (p. 21)

In a systematic review of research done throughout Canada, Duncan et al. (2011) reported that HIV incidence and prevalence rates among Aboriginal peoples were similar to non-Aboriginal people in most risk groups except in people using illicit drugs where it was found that incidence and prevalence for HIV were higher for Aboriginal people (Duncan et al., 2011). These authors also noted that the epidemiological literature often focused on cultural factors

associated with the over-representation of Aboriginal people in HIV incidence and prevalence data, which “shifts interest away from structural violence of social forces such as colonialism, discrimination and poverty, which increase social exposure to HIV” (Duncan et al., 2011, p. 224). The prevailing theme from this research is that the historic and continuing impact of colonization must be acknowledged in the interpretation of why an over-representation of Aboriginal people in HIV incidence and prevalence statistics is observed in Canada. The factors which create vulnerabilities to HIV infection will also create barriers to appropriate treatment and care for Aboriginal people living with HIV.

The influence of colonizing practices on adherence to HAART was addressed in a qualitative study done in Vancouver (Chongo, 2011). This study focused on the determinants of adherence to HAART among Aboriginal men in the downtown east side of Vancouver (Chongo, 2011). Determinants of adherence were categorized as patient factors, interpersonal, support structures, historic trauma and medication related factors (Chongo, 2011). The author states “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” (Chongo, 2011, p. 1). This study demonstrated the multiple and interrelated factors associated with adherence to HAART, and how colonial practices can be linked to challenges facing Aboriginal peoples in HIV treatment.

There is evidence suggesting worse HIV treatment outcomes in northern BC as compared to other regions in BC. The Northern Health Authority was the only health authority in BC with an increasing HIV-related mortality rate from 1987 to 2006 (Lima et al, 2010). The Northern Health Authority had the second highest HIV-related mortality rate in the province, but it is

difficult to ascertain if this rate is simply due to the fact that the HIV infection rate is also high in the Northwest and Northern Interior HSDAs. This evidence suggests that there are significant challenges to receiving quality HIV care and treatment in northern BC.

Common barriers and supports to adherence

In a systematic review, Mills et al. (2006) identified the barriers and facilitators of adherence to HAART most commonly identified in research findings. Common barriers to adherence were “...fear of disclosure, concomitant substance abuse, forgetfulness, suspicions of treatments, regimens that are too complicated, number of pills required, decreased quality of life, work and family responsibilities, falling asleep, and access to medication” (Mills et al., 2006, p. 2039). Common facilitators of adherence were “...a sense of self-worth, seeing positive effects of antiretrovirals, accepting their seropositivity, understanding the need for strict adherence, making use of reminder tools, and having a simple regimen” (Mills et al., 2006, p. 2039). These findings give direction to research looking at potential barriers and supports to adherence to HAART in northern BC, but address only adherence, and are not explicitly linked to social contexts which have an impact on the identified barriers or facilitators to adherence. A discussion of the social determinants of health will facilitate an understanding of how social contexts are related to adherence to HAART and engagement in HIV-related care.

Social Determinants of Health

The World Health Organization (WHO) provides this definition of the social determinants of health:

The conditions in which people are born, grow, live, work and age, including the health system. These circumstances are shaped by the distribution of money, power and

resources at global, national and local levels. The social determinants of health are mostly responsible for health inequities - the unfair and avoidable differences in health status seen within and between countries (WHO, 2013).

Various social determinants of health clearly impact treatment with HAART in a number of ways. People living in marginalized circumstances are the most affected by HIV in British Columbia, which compounds the difficulty in accessing adequate treatment (Johnston et al., 2010). This observation points to the importance of social determinants in understanding barriers or supports to adherence to HAART and engagement in HIV-related care in northern BC. An understanding of the ways the social determinants of health act on an individual or a population's health also requires looking in to how various social determinants interact with one another. The concept of intersectionality is useful in this effort as it forces one to look beyond a single determinant of health or category of social identity in order to "elucidate and interpret multiple and intersecting systems of oppression and privilege" (Hankivsky & Christoffersen, 2008, p. 275). Some of the commonly identified social determinants of health affecting the health of people living with HIV in BC are discussed below.

Food Security

An extremely high rate of food insecurity was found among people on HAART in British Columbia, which has serious implications beyond the effectiveness of HAART (Anema et al., 2011). Anema et al. (2011) found that 71% of participants within their cohort of people receiving HAART in British Columbia were food insecure, and the food insecurity was associated with those participants who earned less than \$15,000 annually, were younger, used drugs, and had depressive symptoms. Studies in Canada and the United States have shown that

food insecurity of people on HAART is linked to poorer adherence, worse virological suppression, and higher mortality rates (Anema et al., 2011).

Housing

Unstable housing is linked to poor adherence to HAART. In a study of people on HAART in BC, it was found that 35% did not have stable housing (Vasarhelyi et al., 2011). Stable housing and food security have been associated with increased viral load suppression and higher CD4 cell counts (Vasarhelyi et al., 2011). These studies surveyed participants primarily from the lower mainland of BC, but it is reasonable to speculate that food insecurity and lack of housing play a significant role in the hardship that people living with HIV face in northern BC as well. Stable housing has also been called a pre-requisite to effective HAART (Cisneros, 2007). Like food insecurity, an unstable housing situation may increase the likelihood that a person views HIV treatment as less of a priority than finding shelter (Vasarhelyi et al., 2011). Also, unstable housing creates risk to personal safety including exposure to the elements or violence. The establishment of a routine as an important factor for adherence to HAART was articulated by Milligan (2011) in a qualitative study which focused on the experience of active injection drug use on adherence for Aboriginal people living in Prince George. The participants' ability to create a regular routine was challenged by "unstable housing, associated morbidities of addiction, other health issues, intergenerational effects of colonization, residential schools and the resulting marginalization, intergenerational trauma, violence, food insecurities, inability to find meaningful work, and societal exile that Aboriginal people of Canada live with today – to name a few" (Milligan, 2011, p. 62). Both adherence to HAART and engagement with health care services can be detrimentally affected by a lack of stable housing, food insecurity and the associated hardships of poverty and homelessness.

Health Behaviours

Issues of access and adherence to HAART are major factors affecting treatment success among people who use injection drugs (Krüsi et al., 2010). Up to 50% of injection drugs users who began HAART in Vancouver, BC, ended treatment early and 60% of those who maintained treatment had suboptimal levels of adherence (Krüsi et al., 2010). Also, hepatitis C co-infection with HIV is seen in higher rates in people who use injection drugs and this creates challenges to treatment because of an increase in the side effects from HAART (Krüsi et al., 2010). People who use injection drugs often face the effects of stigma and social exclusion which can create barriers to treatment; these effects have been reported to be greater for women and ethnic minorities (Krüsi et al., 2010). Milligan (2011) also noted that forgetfulness was one of the primary reasons reported for reduced adherence to HAART for active injection drug users. Illicit drug use has also been linked to a greater risk of unstable housing and food insecurity, which, as discussed previously, can affect treatment success as well (Krüsi et al., 2010). People who use injection drugs may also face repeated episodes of incarceration. Incarceration has been linked to disruptions and discontinuations of HAART (Krüsi et al., 2010). As the primary mode of transmission of HIV in northern BC is injection drug use, a better understanding of the multiple barriers faced by people who use injection drugs in accessing and adhering to treatment is an important step in improving HIV care and treatment outcomes.

Social Networks

Milligan (2011) notes that family, friends and AIDS service organizations are commonly reported as supports to adherence by participants. These relationships were described as supportive by “provision of a steady relationship, food hamper programs, gentle reminder to take

HAART, rides to the pharmacy, and most importantly, the knowledge that someone cared for them” (Milligan, 2011, p. 65). Research also has described how health and social interests can be in conflict particularly when people on HAART skip doses when around friends or family for fear of disclosing their HIV status (Ware, Wyatt & Tugenberg, 2006). These findings indicate the complex roles that social relationships have on peoples’ ability to maintain treatment with HAART. Fear of disclosure and stigma appear to play an important role in whether social relationships create barriers or supports to adherence and engagement in care.

Side Effects

Side effects of HAART can also be a significant problem, although advances in HAART have reduced side effects as well as pill burden (Montaner et al., 2010). A better understanding of peoples’ experiences of side effects with HAART in northern BC is important to understanding how well side effects are managed in this region, how to minimize these side effects, and reduce their impact as a barrier to adherence. Research focusing on the experiences of active injection drug use on adherence for Aboriginal people living in Prince George, BC found that while severe side effects from HAART were reported by participants they were not cited as a reason for missing doses (Milligan, 2011).

Health Care-System

Health care system characteristics have also been linked to barriers to HAART access for people who use injections drug. Krüsi et al. (2010) state “highly compartmentalized health care systems do not easily allow for comprehensive care for HIV-positive IDU (injection drug users) whose service needs are complex and span multiple areas including HIV specialty and primary care, addiction treatment, psychiatric care and hepatology” (p. 6). These difficulties may be

exacerbated in northern BC communities where there are shortages, high turnover rates, or even a complete lack of health care professionals. Highly compartmentalized health care systems, or the need to travel for specialized care, are also likely to create barriers to access to care for people not using injection drugs.

Research investigating adherence to HAART in rural areas in the United States found that the difficulty in adhering to HAART in rural areas was at least equal to, if not greater than, the difficulty in adhering in urban areas (Heckman et al., 2004). Barriers to care identified by people living with HIV in rural areas were the necessity to travel for health care, a shortage of trained medical and mental health care workers, lack of transportation, and stigma within the community (Heckman et al., 1998). While these findings are dated, and from research done in the United States, it is likely similar barriers to care exist in rural areas of northern BC. Stigma associated with HIV status, or illicit drug use, is likely very high in northern BC, and potentially higher in rural and small communities. Added to a potentially high degree of stigma is the fact that confidentiality is a greater challenge in smaller communities, therefore making fear of disclosure another barrier for people who need to access HIV care.

Patient-Provider Relationships

The quality of the patient-provider relationship has been shown to affect adherence to HAART and engagement in care (Beach, Keruly and Moor, 2006). There also is likely a greater power-imbalance between patients living with HIV and their providers, and this imbalance can negatively affect the patient-provider relationship. Mykhalovskiy (2008) found that marginalized people living with HIV in Toronto often felt regulated and controlled by health care professionals, and coerced into beginning HAART. Adherence to HAART is likely to be low if

a patient feels forced into treatment. Mykhalovskiy (2008) also found that community based AIDS organizations often mediated patient-provider power differentials and provided venues for firsthand accounts of HAART in order for people living with HIV to make more informed decisions regarding their treatment options.

The patient-provider power differentials are likely to be great in northern BC where those living in marginalized circumstances are most likely to be affected by HIV. Research conducted by Milligan (2011) reported that “the resounding answer, when asked how HIV treatment could work better for participants, was that healthcare providers need to be more caring” (p. 72). This finding points to potential imbalances in power differentials between patients and healthcare providers. As well, Milligan (2011) also notes that health care providers are viewed favourably if they treated patients as human beings, rather than a diagnosis, and that confidentiality regarding HIV status is critical to many HIV positive patients.

Knowledge Gap

HAART has had a major impact on the HIV epidemic and is a significant component to the treatment and prevention of HIV infection. The quality of HAART is improving which makes it more effective and tolerable for patients. Problems remain with ensuring everyone who needs HAART can receive it, and evidence indicates that this is particularly problematic in northern BC. Research addressing the potential barriers and supports to adherence to HAART has been done in Prince George (Milligan, 2011), but to my knowledge, little or no research has taken place in more rural areas in northern BC. Research on HAART has predominantly focused on adherence. A wider gaze which looks at the many intersecting factors which influence patients’ experience of being on HAART may provide insights which are relevant to improving

treatment and supporting adherence and engagement with HIV-related care. More research is required to understand how best to improve HIV treatment outcomes in this region, and how these needs may differ between more urban centres like Prince George, and more rural areas like Smithers, BC. In the following chapter I discuss the methods I used to conduct my research.

Chapter 3: Methodology

The goal of this research is to better understand the experiences of people prescribed HAART in northern BC in order to identify and better understand the barriers and supports to adherence to HAART and engagement in HIV-related care in this region. In order to do this I used an interpretive phenomenological approach with interviews as the primary data collection method.

Research question

The central question of my research is what barriers and supports to adherence and engagement in HIV-related care are experienced by people prescribed HAART in northern BC? In identifying and facilitating a better understanding of these barriers and supports it will be possible to look at ways in which to improve HIV care in this region.

Approach/Methodology

Qualitative methodologies, in contrast to quantitative methodologies, emphasize “discovery, description and meaning rather than prediction, control and measurement” (Laverty, 2003, p. 2). The epistemological frameworks of qualitative and quantitative research are often dichotomized as subjective versus objective (Kvale, 1996). Kvale (1996) argues that the interview cannot be classified as an objective or subjective method, but rather an intersubjective interaction. While the interview process can be characterized as an intersubjective interaction, it is accepted within a phenomenological approach that researcher subjectivity is inevitable (Finlay, 2009).

Several different methodologies are available in qualitative research. I have chosen to use interpretive phenomenology. Phenomenology is a philosophical tradition as well as a strategy of qualitative inquiry where the focus is on understanding the essence of human

experiences (Creswell, 2003). Phenomenology as a philosophy was developed by Husserl, but different phenomenological traditions have emerged (Kvale, 1996). Lopez and Willis (2004) identify and contrast two phenomenological approaches commonly used in qualitative health research; descriptive phenomenology based on Husserl's philosophy and interpretive phenomenology developed from Heidegger's ideas (Lopez & Willis, 2004). An important difference between the two approaches is the extent to which a researcher's prior knowledge and experiences should influence the research. Within a descriptive phenomenological approach a researcher's presuppositions are to be set aside, a process known as bracketing, in order to reduce bias (Lopez & Willis, 2004). In an interpretive phenomenological approach bracketing is not appropriate and a researcher's prior knowledge and experiences play an important role in the research process. My own assumptions, which are linked to my experience of growing up in Telkwa, a small town in northern BC, are discussed below.

Interpretive phenomenology seeks to understand complex social phenomena from the perspective of those who experience the phenomena, and is grounded in a hermeneutical philosophical stance (Lopez & Willis, 2004). A philosophical assumption of interpretive phenomenology is that the knowledge of the researcher is an important guide within the research process, but preconceptions and the potential impact of preconceptions on the research need to be transparent (Lopez & Willis, 2004). Another philosophical assumption of this approach is the concept of situated freedom which states that "individuals are free to make choices, but their freedom is not absolute; it is circumscribed by the specific conditions of their daily lives" (Lopez & Willis, 2004, p. 729). This assumption links the subjective experiences of individuals to social, cultural and political contexts (Lopez & Willis, 2004). A related concept is what Heidegger termed the lifeworld, which articulates "the idea that individuals' realities are

invariably influenced by the world in which they live” (Lopez & Willis, 2004, p. 729). These assumptions within interpretive phenomenology guide the research methods to be used, and are the reasons why I chose this particular methodology; they focus the research on the experiences of the participants and their relation to their lifeworlds, and allow the use of concepts, theories and experiences of the researcher to guide the research process.

Positioning Statement

A positioning statement is one way of making transparent the preconceptions of the researcher and the following is my positioning statement.

I was born in Smithers, BC in 1984. My parents, Harald and Kay, moved to Smithers in 1972 from Vancouver for my father’s job as a high school English teacher. Both of my parents immigrated to Canada; my father from Germany, and my mother from the United States. Both of my parents had very different experiences during childhood. My mother grew up in the United States in a middle class Catholic family with Irish ancestry, and my father in Germany. Being born in 1944 my father spent his early years in a refugee camp, then when he was 9 years old he fled to West Germany with his family. Despite these difficult circumstances I did not feel as though they were particularly traumatizing to my father, which is likely due to the strong support he received from his mother.

I grew up in Telkwa, BC, just outside of Smithers, along with my two older sisters. Looking back on my childhood I can see that I was very fortunate for many reasons. My family was loving, stable, and supported me in my goals without pressure. Social justice, while not explicitly named as such, was an important value in my home, and pursuing a career which was both one I was interested in and in which I would find fulfilling because of the value of the work

was encouraged. From a young age I remember being aware of current events and politics because of the influence of my parents, and often discussions about events both local and global were times where my parents engaged me in the dialogue and expressed their opinions and values. My childhood was also somewhat sheltered, and my peer group, and that of my parents, was predominantly made of friends from similar backgrounds.

After high school I attended the University of Victoria and majored in Biology. Upon completion of my undergraduate degree I had the urge to travel. I took a volunteer position with a Canadian NGO to go to Tanzania for 10 weeks. I now look to this experience as being one of the most influential of my life, and one which created my interest in studying HIV. The projects which the NGO worked on in Tanzania were primarily related to HIV education, but they were also involved with local associations of people living with HIV. Prior to leaving I read much about HIV in Africa, and around the world. Much of what I read pointed to social, economic and political factors associated with the epidemic. Working with and getting to know people living with HIV, I learned quickly that being HIV positive did not define who they were as people. I also learned of the many challenges faced by people living with HIV which were rooted not only in the physiological impact of HIV, but in the social world as well. Poverty and stigma were two forces which previous to my experiences in Tanzania I had only a theoretical understanding of. After getting to know people who faced these challenges daily, my understanding of these forces had a more personal component to it. It was my experiences in Tanzania which have motivated my interests in studying HIV.

I returned to the University of Victoria and undertook a second degree in Anthropology. The courses in Anthropology offered me new ways to look at the world, as well as how to critically analyze social structures. I also became more interested in the HIV epidemic locally,

and volunteered with AIDS Vancouver Island. After completing this degree I felt compelled to return to northern BC, and to begin graduate studies and to focus my research locally within the region I grew up in.

A few months after having completed the recruitment of participants and all interviews for this research I was hired as an Outreach Support Worker with the community-based AIDS organization (CBAO) which I partnered with for recruiting participants. I worked part-time with the Medication Adherence Support Program (MASP) which was a joint project of the Northern Health Authority, Central Interior Native Health Society (CINHS) and the CBAO. In this position I worked with clients who were identified as having, or potentially having, particular difficulties in adhering to either antiretroviral medications, or tuberculosis medications. This position gave me greater insight in to the challenges faced by those living with HIV in marginalizing circumstances, as well as the functions and constraints of the healthcare and social service systems. I worked with clients to find housing, pick up food from food hampers, provide rides to medical appointments, and deliver medications to name a few of the regular duties. Building relationships and trust with clients was integral to this position as well, and I made it a priority to have conversations with clients which would allow them to get to know me, and for me to get to know them. I left this position at the end of August 2013 to pursue further educational opportunities.

In summary, my experience and background have shaped my value system which I would describe broadly as humanistic, with equity and social justice being ethical foundations. To paraphrase a former professor I believe that treating everyone equally is not the same as treating everyone fairly. People are diverse and have different needs which need to be acknowledged. I believe that to feel fulfilled in what I am doing the work must have a

component where I can provide a useful service to others. I also believe that social influences on health and well-being are too often overlooked, and underemphasized. I see social processes as being fundamental to any understanding of the disparities in health between groups of people. I also have biases and blind spots which may affect interpretations in this research. Only a few times in my life did I experience being a minority, and I rarely have felt any form of discrimination as a non-Aboriginal Euro-Canadian male. I am potentially less attuned to the impact of discrimination on others because of my economic status, race, gender and sexual orientation.

Clearly this positioning statement has provided an abbreviated narrative of my life and expression of my values, but what I have chosen to include are important moments and perspectives which, as I look back now, were relevant to my choices in undertaking this research, and also point to my preconceptions which have an influence on the research I have done and the interpretations I have made.

Orienting Framework

An orienting framework grounded in theory was used to inform the research, and make explicit my assumptions and frame of reference as a researcher (Lopez & Willis, 2004). The orienting framework was also used to guide the presentation of data in the results section, and inform a discussion of the results in chapter 5. Three inter-related theoretical concepts will be used to make up this orienting framework.

The first theoretical concept which comprises the orienting framework of this research is an understanding of the social determinants of health based on Reading and Wien's (2009) *Integrated Life Course and Social Determinants Model of Aboriginal Health*. In this model the

social determinants of health are further classified as acting at proximal, intermediate and distal levels (Reading & Wien, 2009). Proximal determinants of health have a direct impact on peoples' health and can include one's physical environment and behaviours (Reading & Wien, 2009). Intermediate social determinants of health include health care and educational systems, and these have an impact on the proximal determinants (Reading & Wien, 2009). Distal social determinants of health include the "political, economic and social contexts that construct both intermediate and proximal determinants" (Reading & Wien, 2009). These three levels are interrelated and the more distal level influences the proximal level, where the mechanism of influence on one's health can more easily be identified. Linking the proximal level to the intermediate and distal levels of influence is an important task in understanding differential distributions of health and illness within a population, and also allows one to identify large scale policies which may help or hurt a population's health (Reading & Wien, 2009). The presentation of data in chapter 4 of this thesis primarily uses the proximal and intermediate social determinants of health as a way to organize and present the data. The distal social determinants of health are addressed in the discussion of this thesis because participants' comments primarily addressed their own experiences, and comments rarely were explicitly linked to distal factors.

The second theoretical approach is the biosocial approach to adherence described by Castro (2005). This approach is "...grounded in an understanding of adherence as biological and social process that changes with time, and must be framed within an analysis of access to health care and medications (Castro, 2005, p. e338). This approach specifically identifies biosocial variables important to an understanding of adherence to HAART (Castro, 2005). These variables are categorized as socioeconomic factors, health-care system, social capital, cultural models of health and disease, personal characteristics, psychological factors, clinical factors and

antiretroviral regimen (Castro, 2005). A biosocial approach to understanding adherence acknowledges the social determinants of health, which play a significant role in both the distribution of HIV infection within populations, as well as in distribution and quality of HIV care within a population. The biosocial approach advocated by Castro (2005) addresses both the social and individual factors related to treatment with HAART. Also, this approach guides an analysis of the data in several ways. First, attention is paid to ways that participant's experiences with HAART are not static, but change over time. Second, understanding treatment with HAART as both a biological and social process influences the analysis of data in that attention is paid to how experiences of biological phenomena, such as a side effect, can be experienced at a social level. Finally, Castro (2005) advocates framing an understanding of adherence with an analysis of access to medication and care, and such an analysis guides the interpretive process.

The final concept which comprises the orienting framework is structural violence. This term is used to describe the way in which various social structures (economic, political, cultural, legal, religious) cause harm to people and populations (Farmer et al., 2006). Using structural violence as a concept to aid in understanding peoples' health and illness emphasizes the fact that social structures which place individuals, groups or societies in harm's way are unjust. Farmer, et al, (2006) deconstructs the term by stating "the arrangements are structural because they are embedded in the political and economic organization of our social world; they are violent because they cause injury to people (typically, not those responsible for perpetuating such inequalities)" (p.1686).

In using the concept of structural violence in research, Farmer (2004) advocates linking the ethnographically visible, for example the experiences of people living with HIV, to the ethnographically invisible, such as social structures which create barriers to treatment with

HAART. Finding the linkages between the ethnographically visible to the invisible is a similar task as making links between the proximal, intermediate and distal social determinants of health and as such structural violence can also be thought of as a descriptor for an unjust distal social determinant of health. An analysis and interpretation of the data are required to make explicit the connection between participant's experiences and structural violence, therefore this concept will be explored in the discussion in chapter 5, rather than be a category of analysis in the results presented in chapter 4.

These three inter-related concepts bring unique ways of looking at research and data related to the barriers and supports to adherence to HAART and engagement in HIV-related care in northern BC. Evidence indicates that factors influencing adherence to HAART play out at multiple levels (Castro, 2005), and this is even more true when expanding one's gaze from adherence alone, to engagement in HIV-related care as well. These three concepts comprising the orienting framework for this study also are congruent with the methodology of interpretive phenomenology as they all acknowledge how individuals are embedded within their social worlds.

This research investigates the phenomenon of being on HAART in northern BC in order to identify and understand the barriers and supports to adherence and engagement in care. It is the experiences of those who are being treated with HAART which informs this research. The aim of this research is to provide a better understanding of this phenomenon, to inform the ways to improve HIV care.

Method

Purposive sampling was done to select participants in this study. There were two separate sample populations. All participants were required to be above the age of 19. Inclusion criteria for the first and primary sample population were current residence within the Northwest or Northern Interior HSDAs and current treatment with HAART. This sample had 8 participants, 2 being recruited in Smithers, BC, and 6 recruited in Prince George, BC. Prince George had a population of 75, 828 according to 2011 census data, a median income of 27, 670 dollars in 2006, an 11% prevalence of people who are considered low income, and an average gross rent of 656 dollars in 2006 (BC Statistics, 2012). Smithers had a population of 5, 347 according to 2011 census data, a median income of 25, 884 dollars in 2006, a 12.7 % prevalence of people who are considered low income, and an average gross rent of 567 dollars in 2006 (BC Statistics, 2012). Smithers is considered rural while Prince George is considered urban (Statistics Canada, 2008). However, while most participants interviewed in Prince George had lived there for several years, most moved to the city from rural communities.

The inclusion criterion for the second and smaller sample population was employment at a community-based AIDS organization (CBAO) where the 3 participants made up this sample. The purpose of including employees of a CBAO was to complement the interview data from those who are on HAART by including the perspectives of service providers. In total 11 participants were interviewed. Demographic characteristics of participants are displayed in table 1.

Table 1 *Demographic characteristics of participants.*

Participant	Sex	Type of interviews	Age	Years since HIV diagnosis	Years on HAART
1	Female	Person on HAART	41-45	10-15	Less than 1
2	Male	Person on HAART	41-45	10-15	10-15
3	Female	Person on HAART	35-40	6-10	1-5
4	Female	Person on HAART	25-29	1-5	1-5
5	Male	CBAO worker	N/A	NA	NA
6	Female	Person on HAART	46-50	1-5	1-5
7	Female	Person on HAART	41-45	6-10	1-5
8	Male	Person on HAART	35-40	10-15	6-10
9	Male	CBAO worker	N/A	NA	NA
10	Male	Person on HAART	41-45	1-5	1-5
11	Female	CBAO worker	N/A	NA	NA

Recruitment of participants was done through a community-based AIDS organization (CBAO) which had offices in Prince George and Smithers BC. The role of the CBAO in participant recruitment consisted of mentioning this study to people who were known to be taking HAART and who may be interested in participating. A Participant Recruitment Information Sheet was given to the CBAO to provide to potential participants (attached in Appendix). As well, the CBAO was asked to pass along contact information of the researcher to interested participants. It was crucial that the interview process took place in “an environment of safety and trust, that needs to be established at the outset and maintained throughout the project” (Lavery, 2003, p. 19). The locations of the interviews were chosen so that both participants and

researcher considered the location a safe place. All interviews were conducted in the offices of the CBAO.

Prior to data collection, informed consent was attained from participants and participants signed a consent form. The method of data collection was semi-structured interviews which ranged from 15 minutes to 1 hour. Questions were open ended with the aim of eliciting rich descriptions of the participant's experiences with HAART. All interviews were audio recorded, and transcribed by the researcher.

An initial interview was done with all participants while follow-up interviews were done with all but one participant. Follow-up interviews occurred after an analysis of the original interview was completed. During follow-up interviews participants were given the option to read the transcript of their original interview. Follow-up interviews served to verify interpretations, as well as provide an opportunity for questions formulated through the interpretation phase to be asked.

Ethical concerns

Confidentiality of participants is a primary concern due to the potential stigma faced by people living with HIV in northern BC. Various steps were taken to protect confidentiality of the participants. First, participant recruitment was done through a CBAO whose staff are aware of issues related to confidentiality regarding HIV status. Second, when the researcher contacted potential participants, a mutually agreed upon setting was chosen for the interview. The agreed upon location was one considered a safe place to both the researcher and the participant, and provided a private setting to ensure confidentiality during the interview. All interviews took place within the offices of a local CBAO. Participant names only appear on consent forms, and

identifiers were removed from interview quotes provided in the results section. The protocols for confidentiality of participants were discussed with participants and outlined in the letter of consent. However, due to the nature of research within small communities anonymity was not guaranteed, and this was made clear to participants and stated in the letter of consent.

Another ethical concern was that the interview process did not cause participants undue stress. To ensure that the interview process did not cause significant amounts of stress the voluntary nature of participating was made clear, and an honorarium of \$10 was guaranteed even if participants did not complete the interview. Funding for this honorarium came from the investigator. Also, information for counselling and support services was offered to participants in case these services were required due to emotional stress caused by the interview process. This research was approved by the University of Northern British Columbia Research Ethics Committee.

Data analysis technique

Interviews were transcribed and coded after completion. The software program NVIVO 8 was used to manage data. The coding process was dynamic and inductive, and a codebook was developed, and refined throughout the research process. The codebook followed the structure described by Fonteyn et al. (2008) and included the code, a definition of the code, inclusion and exclusion criteria, and an example text. Coding is a way to organize the transcriptions into more manageable concepts and is also a part of analysis and interpretation (Ryan & Bernard, 2000). Codes were developed through a process of thematic analysis, and each code corresponded to a specific theme (Fereday & Muir-Cochrane, 2006). Thematic coding was initially broad in subject matter with codes being refined throughout the analysis of the data. Boyatzis (as cited in Fereday & Muir-Cochrane, 2006) describes a theme as “a pattern in the information that at a

minimum describes and organizes the possible observations and at a maximum interprets aspects of the phenomenon (p. 83).”

Analysis, or explication, within interpretive phenomenology requires an understanding of the context in which dialogue was produced (Lavery, 2003). Self-reflectivity on the part of the researcher is key to the interpretive process, and to achieve this, a reflective journal was kept by the researcher during the research process to aid in interpretation as well as reflection on how the researcher’s assumptions impact interpretation (Lavery, 2003).

The validity and reliability of the research and interpretations can be understood in interpretive phenomenology as issues of rigor (Lavery, 2003). Critical to achieving rigor are the “multiple stages of interpretation that allow patterns to emerge, the discussion of how interpretations arise from the data, and the interpretive process itself” (Lavery, 2003, p. 23). With all but one participant, follow-up interviews were conducted where key themes from the initial interviews were checked. Follow-up questions were also asked, and when interpretations of the initial interview had been made these interpretations were checked with participants. However, the interpretive process continued after all interviews were conducted, and therefore it was not possible to verify all interpretations with participants.

The interpretive process was dynamic, and was guided by Kvale’s (1996) description of the seven hermeneutical cannons of interpretation. The first cannon relates to what is known as the hermeneutical circle which can be described as a “back and forth process between the parts and the whole” (p. 48) of the text (Kvale, 1996). A basic understanding of the whole text leads to an interpretation of a particular part of the text, which can lead to a re-interpretation of the whole text. This back and forth process took place throughout the analysis and interpretation

phase of research where an interpretation within one interview transcript was considered in relation to entire text, and then in relation to all other interviews. The second canon states the point to end one's interpretation of a text is "when one has reached "good gestalt," an inner unity of the text free of logical contradictions" (Kvale, 1996, p. 48). In my case, the focus of my interpretations was narrowed to factors which fit within my orienting framework to make the data set more manageable, and within this circumscribed focus I achieved what I felt was a "good gestalt." Testing one's interpretation of a part of the text against the meaning of the whole text makes up the third canon (Kvale, 1996). This testing of part of the text against the whole was done as part of the back and forth process described by Kvale (1996) as his first canon. In my position working as an outreach worker I often found myself considering interpretations from my research in relation to the circumstances of clients of the adherence support program. My experience with MASP typically reinforced interpretations from research interviews, and these will be further discussed in chapter 6 of this thesis. "Autonomy of the text" (p.48) is the fourth canon and it places the content of the text as the primary source for interpretation (Kvale, 1996). The text was the primary source of interpretation, but as mentioned, my work experience also played a role in how I interpreted the text, as well reading of the academic literature on related topics. The fifth canon regards the importance of the interviewer's knowledge of the theme which enables the interviewer to be "sensitive to the nuances of meanings expressed and the different contexts into which the meanings may enter" (Kvale, 1996, p. 49). My sensitivity to nuances of meaning likely increased during the process of interpretation because of my position as an Outreach Support Worker. Witnessing the difficulties associated with homelessness or food insecurity provided a deeper understanding of participants comments related to these issues, to name a few. The sixth canon regards the understanding that interpretations are not

“presuppositionless”, but presuppositions can be made explicit and therefore how they influence the interpretation can be made clear (Kvale, 1996). My presuppositions can be identified through the positioning statement and the orienting framework and literature review. A presupposition central to my interpretations is that the benefits of HAART should be accessible to all those who can benefit. Barriers to achieving the benefits of HAART which are rooted in social, economic or political forces are social injustices which cause harm. The final canon refers to how interpretation is an innovative and creative process which “...enriches the understanding by bringing forth new differentiations and interrelations in the text, extending its meaning” (Kvale, 1996, p.50). Throughout the interpretive process I often felt overwhelmed by the complexity and interrelatedness of the data, and how to present the findings without oversimplification. To manage this complexity the focus was narrowed to primarily look at the factors relating to the social determinants of health. Having this focus allowed the interrelations between proximal, intermediate and social distal determinants of health to be made in a more straightforward manner.

Limitations of this study

The study design has several limitations. First, as a CBAO was the only site of participant recruitment only those who access this CBAO were recruited. Therefore the selection of participants may be skewed towards those who require more support, and therefore may be more likely to have greater challenges with adherence and engagement in care. Second, the original intention was that a similar number of participants would be interviewed at both sites, but as it was more difficult to recruit and interview participants in Smithers there were fewer interviews done there. The fewer number of interviews done in Smithers is likely partially due to fewer people living with HIV and on HAART in Smithers, but also may be due to a greater fear of HIV

related stigma. Therefore, the selection of participants interviewed in Smithers may have been skewed towards those who were more open about their HIV status. Finally, all coding, analysis and interpretation was done by a single researcher thereby increasing the risk of bias, or overlooking relevant data. This makes the positioning statement and the orienting framework particularly relevant for understanding my potential biases.

The next chapter presents the results of my study and organizes these results in sections focusing on the proximal and intermediate determinants of health, a geographical analysis and participant comments relating to how their Aboriginal ancestry affects their treatment with HAART.

Chapter 4: Results

This study set out to investigate the experiences of people prescribed HAART in northern BC with the goal of identifying and understanding the various barriers and supports to adherence to HAART and engagement in HIV-related care in order to inform ways to improve HIV care and treatment outcomes in this region. This chapter presents the results of this research. Results are organized around the proximal and intermediate social determinants of health which comprise the bulk of this section. Figure 2 provides a graphic representation of the connection between the proximal, intermediate and distal social determinants of health. A geographic analysis presents results which highlight the differences in participant experience of HAART related to their residence in either Prince George, or Smithers BC. Finally, results are presented which focus on participants' experience of being Aboriginal and the relationship their ancestry has to factors related to adherence and engagement in care.

Figure 2. The relationship of the proximal, intermediate and distal social determinants of health to the lived experience.



HAART and the experiences of the proximal social determinants of health

It is the proximal social determinants of health which have the most direct influence on participant experience as these directly impact “physical, emotional, mental or spiritual health” (Reading & Wien, 2009, p. 5). The quality of social relationships, housing, education, income, and health behaviours comprise some of these proximal determinants (Reading & Wien, 2009). These proximal determinants influence participant’s adherence to HAART and engagement in HIV-related care through multiple direct and indirect mechanisms. Components of the proximal social determinants of health which appear to be particularly relevant to adherence and engagement in HIV-related care and to be presented in this section are social supports, stigma and disclosure, housing, food security, income and accessing financial assistance, and substance use. Presentation of results related to the intermediate social determinants of health, as well as results related to geographical location, and Aboriginal ancestry will follow this section.

Social support. Social supports impact participant’s experience of being on HAART in a variety of ways. Participants most readily commented on ways friends, partners or family provided emotional support, particularly with respect to dealing with an HIV positive diagnosis, but also commented on tangible supports, such as rides to medical appointments, or informational supports specific to HIV care. Results regarding the social supports provided through a CBAO will be discussed in a different section of this thesis.

One participant described the emotional support received after his HIV diagnosis demonstrating the importance of having a supportive relationship during a time of crisis.

And I went to the doctor and he said your HIV test is positive, and fuck, oh my goodness, my god, you know. So I just, I never went back to work. I just went straight home I mean

I was in complete and total shock. I mean I was just in shock, shock. And I, my, the phone rang and it's my boss at three in the afternoon and I just froze, what the fuck do I do, so I um, I phoned her back and I told em my HIV test was positive and she hung up the phone and came over to my house and stayed with me till about 8 o'clock that night. And it was really, really a lot of really good support that way. Umm, so yeah I had some pretty reasonably good support (Client, Interview 2).

Several participants cited their partners as significant sources of support. One participant whose partner was also living with HIV indicated the importance of this relationship.

Yeah. She's (*partner*) positive too. We look after each other. And it really helps (Client, Interview 8).

Emotional support from others living with HIV was also described by some participants as being an important source of social support, particularly when the fear of stigma and social exclusion was strong.

(*community centre*), and (*shelter*), (*shelter name*) is a woman's shelter so there is a couple of women that have the same diagnose as me, and it's um very confidential there, I guess that's why I feel comfortable (Client, Interview 1).

Relationships can provide both emotional and tangible supports which can aid adherence to HAART and engagement in care. The importance of emotional supports appears to be that they can support one's mental health, such as reducing depressive symptoms which have been linked to reduced levels of adherence (Gonzalez et al., 2004; Simoni et al., 2006). Other supports, such as a ride to a health care appointment, a reminder to take medication, or guidance or information about treatments demonstrate a direct link to how social relationships can

improve one's treatment with HAART through increased adherence and engagement with health care services.

The level and quality of social support participants received varied greatly among participants and appeared to be linked to other proximal social determinants of health. Participants whose comments demonstrated greater levels of social support had greater stability in their lives in terms of income, housing status and were less likely to have an active addiction to drugs and/or alcohol. Participants, whose comments indicated low levels of social support, also indicated having greater challenges with housing quality, and drug and alcohol use, and described a higher frequency of missed doses of HAART, and greater dissatisfaction with health care provision. Unfortunately those with the greatest need of the supports provided through social relationships were those who typically had fewer of these supports.

Stigma and discrimination. As positive social relationships provide significant supports to those on HAART, negative social interactions can create barriers to adherence and engagement in HIV-related care. Participants' experiences of stigma based on their HIV status, and the effect those experiences had on participants varied, but all commented to some degree about their experiences of stigma. Stigma and discrimination was not limited to HIV status as participants discussed various forms of discrimination, including racism, or discrimination based on perceptions of substance abuse. However, this section will focus on participant experiences of HIV-related stigma. Also, stigma affected not only the individual living with HIV, but as one participant described, was directed towards her children as well.

Yeah, just the stigma of HIV period, everybody thinks it's a gay man's disease, or you're dirty, or it's caught by needles, or not sex, and all this. I don't know people really need to

get more educated on it. I think. I think they need to go in to the schools at a younger age, not, not like grade 7 grade 8, but at least grade 4, grade 5 and start talking about, about it and stuff you can do for it, or prevent it. It's yeah, it's sad, um the only thing I regret about being so open about it is my kids get bugged in school for it (Client, Interview 4).

One participant described the social isolation she feels because of the stigma towards people living with HIV.

I got through a lot of people putting me down cause I have it, so when society is like that we keep it a secret, don't blame us for that, it's the coil of embarrassment is what we're trying to hide, and the coil of denial, regret, boycott, I guess from the real clean healthy people. We're still separated mentally, in a drug store, in a party, in medical office, we're drawn closed, um, if there was a way, there is, they're already advocating HIV days and stuff, but, it still is embarrassing and I think HIV is more embarrassing than cancer is (Client, Interview 1).

Stigma, or the fear of stigma, can create barriers to a patient's treatment with HAART in a number of ways. Several participants linked experiences of, or fears of stigma, as being factors contributing to their stress, anxieties and feelings of depression, all of which are associated with reduced adherence to medications (Vanable et al., 2006). Stigma as a stressor also may contribute to the use of drugs and/or alcohol as a coping strategy which can negatively impact adherence, as well as engagement in health care. Research has found lower levels of adherence among those who use drugs and alcohol as coping strategies to deal with the stress of being HIV

positive (Power et al., 2003). A fear of being outed as HIV positive also can reduce adherence or engagement in HIV-related health care.

Experiences of stigma and discrimination are sources of significant stress for many participants, but there appear to be factors which mitigate how these experiences of stigma impacted participants. Having more social supports, an acceptance of being HIV positive, and a greater sense of self-worth appear to reduce some of the negative effects of stigmatizing experiences, while having fewer supports, struggling with accepting one's HIV status and lower self-worth appear to be factors which exacerbate the impact and potential consequences of a stigmatizing experience.

Stigma must also be discussed in terms of one's ability to avoid stigmatizing experiences, and one's level of control in maintaining privacy regarding his or her HIV status. One participant who commented on not wanting to take her medications because of a fear of being outed also commented on living in an apartment shared with others. Had her housing situation provided more privacy she would have been able to take her HAART medications without the fear of being outed as HIV positive. Similarly those who live in supported housing, or use shelters, or frequent soup kitchens are less able to control their environments, and therefore have less control in avoiding potential stigmatizing experiences, and controlling their HIV disclosure. The control of one's environment is influenced by the available options in terms of where to live, where to get food, and who to associate with. Greater access to resources allows for more options and therefore more control of one's environment. Therefore, there is likely a link between one's probability of a stigmatizing experience and one's socioeconomic status because those with a low socioeconomic status who are dependent on services to meet basic needs, such

as food and shelter, have less choice in where these services are accessed and who one associates with.

Disclosure of HIV status. Participants' comments regarding their feelings about disclosure of HIV status are closely linked to their experiences and perceptions of stigma. Several participants discussed the anxiety felt trying to hide their HIV status, especially from family members.

You don't know what the anxiety is coming from, is it because I've just been diagnosed with this horrible disease, I don't work, my son's asking me why and, and your life becomes just one big lie, you end up just lying and lying and lying. I never told my son for a year and a half. I never told family members for well over a year, I never told neighbours. 'But why don't you work anymore (*name*), why have you lost 30 pounds (*name*),' and you just end up, it's very tiring after a while (Client, Interview 2).

These anxieties not only increase the stresses in one's life, but for one participant her fear of others finding out her HIV status lead to her leaving her job.

But I still worked, but I, mentally got me down after the fourth year in the (*place of employment*), sitting there, crash, can't work around people cause you don't want them to find out you have it. It could be devastating to them, but you would be more devastated cause the embarrassment is a heavy burden (Client, Interview 1).

One participant articulated her decision to be open about her status because attempting to hide it caused significant stress and anxiety, and because she felt it was extremely difficult, if not impossible, to keep her HIV status private in a small town.

I just found it was easier to be open about it than hiding it cause it's made me feel more down about myself, having to hide it and knowing that somebody already knew, and then you're, somebody asks you and you're like no, and they're like, oh I heard this person said you had it, so it's like yeah whatever (Client, Interview 4).

For some, disclosing one's HIV status with family and close friends reduced stresses and allowed beneficial social supports, such as reminders and encouragement regarding medication adherence. These outcomes of disclosing one's HIV status therefore can support one's treatment with HAART directly through illness-related support and indirectly through less anxiety, stress and depression (Vanable et al., 2006). This finding is congruent with a study which identified being open about one's HIV status and receiving social support as a central theme voiced by excellent adherers (Malcolm et al., 2003). However, other participants commented on facing stigma or social exclusion from family members when their HIV status became known. These outcomes added stress and anxiety, and ultimately decreased the level of social supports; all these factors are likely to create more challenges in one's life, and more barriers to adherence and engagement in care.

The risks or benefits involved with disclosing one's HIV status differ for every individual, but there appears to be a link between one's socioeconomic status and whether one's disclosure of his or her HIV status supports or hinders his or her treatment with HAART by affecting adherence, or engagement with health care services. Another study of people with high rates of adherence demonstrates that high adherers "...were able to manage the environment by recognizing positive and negative sources of support. They assessed their support systems as appropriate, gauged their level of disclosure and avoided stressful people and situations" (Lewis, et al., 2006). As discussed in the previous section on stigma, the level of management and

control of one's environment is not always possible for those relying on shelters or other forms of shared low income housing or community services, thus as with experiences of stigma, control of disclosure of one's HIV status, and the outcomes of that disclosure likely are influenced by one's socioeconomic status.

The previous sections discussed the way social relationships can help or hinder adherence to HAART and engagement in HIV-related care for those living with HIV. The following sections will discuss some of the structural factors including housing, food security and income, which play a role in creating barriers or supports to adherence and engagement in care.

Housing. Stable housing has been shown to be an important factor for successful treatment with HAART and has been linked to decreased viral loads (Hawk & Davis 2012; Varsarhelyi et al., 2011). All but one participant in this study described their housing situation as stable, but there are likely differences in what each participant regarded as stable housing. Several participants described having been homeless, or living in inadequate housing at some point in their lives. Participants' housing situations at the time of interviews included a shared single room occupancy rental, a shared apartment, a mobile home, a shelter, a supported housing unit, a shared home, and rented basement suite. Three participants commented on improvements in their housing situations lead to improvements to adherence or better access to health and social services. One participant cited moving to more stable housing as improving her access to care because the new housing location allowed easier access to medication pick up, and other services.

Because, um, they (*CBAO and primary care clinic staff*) got me out of the living conditions I was in, which was basically like a broken down little dog house, um, back in,

in an area where people just wouldn't even have known that I was there (Client, Interview 6).

Another participant cited moving from a shared room in a shelter to a supported housing unit with a private room as improving her well-being, and enabling greater adherence because support staff reminded her to take her medications.

Yeah, they're (*housing staff*) helping me. So they come and check if I've taken my medication. It's pretty, they monitor me eh, they sort of keep an eye on me to make sure I take my meds (Client, Interview 7).

This participant also commented on how having a private room made it easier to manage her addictions.

It's easier because um, I'm not around people that are intoxicated and it's, it's better for myself (Client, Interview 7).

These comments point to the fact that there are factors related to one's housing which influence adherence to HAART beyond simply if housing is stable or not. Privacy, location, and the presence of support staff are a few of these factors commented on by participants. Another factor which appears to be important but was not directly commented on is the reduced level of personal autonomy some face when living in a shelter or supported housing unit. Evidence for the importance of autonomy in one's housing situation comes from one participant's complaint of the quality of food provided in the housing unit and the stress this caused, as well as from literature on personal control and stress, and my own experience working with clients of an adherence support program who lived in shelters.

Clearly individual socioeconomic status, as well as housing infrastructure within a community affects the quality of housing one can access. The stresses and resultant instability caused by inadequate housing situations create various barriers to adherence and engagement in care, such as the difficulty in maintaining a regular routine, a lack of privacy leading to missed doses because of a fear of being outed, or housing needs taking a greater priority over one's health care needs. A service provider commented on his observations of the difficulties associated with being homeless and on HAART.

If you, and I do believe, I do believe, most people if there was some level of stability would participate in the medication, would do it. But, just you know, sleeping in the bush in the summer and begging a room in the winter, that's no lifestyle to, to try some sort of you know regular medical regimen of everyday, everyday, everyday, everyday (CBAO worker, Interview 5).

Food security. Slater (2012) describes food security as being “achieved when all people have the physical and economic means to access, at all times, sufficient, safe and nutritious food that meets their dietary needs and food preferences for an active and healthy life” (p. 1). Most participants commented on using soup kitchens or food hampers as significant sources for meeting their nutritional needs. This reliance indicates that without these services there would likely be much greater food insecurity in these communities. As one participant articulated, financial constraints create significant challenges to getting healthy food.

Yeah just trying to get proper nutrition like good healthy foods is, by the time I paid my bills and all that I'm, I'm pretty much tapped, like maybe 50 dollars for the month, which is nothing. Like nothing, especially if my kids are over (Client, Interview 4).

The high use of food hampers and soup kitchens also indicates that these participants have less control over what foods they have access to and when. This lack of control is particularly problematic when dietary needs are more restricted and complicated because of HIV infection and use of HAART medications. Timing meals with medications and choosing foods that interact well with medications are important components to some HAART regimens to enhance therapeutic value and/or mitigate side effects (Slater, 2012). One participant commented that her food needs are unique, but not being adequately met at her supported housing residence. This lack of appropriate foods caused both physical and emotional distress.

Um, yeah, yeah, if it wasn't for getting the food here (*CBAO*) I would be starving, way worse, because like I say, (*housing*) doesn't um, they get their meals from the (*community agency*) and they figure that's it, um it comes in one big slop bucket, and that's for the whole, all the girls right, all the women or whatever. And I, I can't eat it, because so much of it will make me sick (Client, Interview 6).

Having less control over one's food may potentially impact treatment with HAART in a number of ways. The lack of control over one's food may induce stressors, or reduce one's ability to meet more complicated nutritional requirements, and potentially impact adherence. As mentioned earlier the reliance on soup kitchens also decreases one's control of one's social environment which may be stress inducing as well, and may lead to persons avoiding needed nutritional supports.

While these negative consequences exist the benefits of food hampers and soup kitchens should not be underestimated. Without these services food insecurity would be much greater. Accessing food hampers and soup kitchens may provide opportunities for building relationships, and a sense of community, and enhance access to a variety of social or health related services,

which could ultimately support adherence and engagement in care. However, the high rate of food insecurity among participants ultimately speaks to the fact that poverty creates barriers to meeting even the most fundamental of human needs. When food security is problematic people are likely to put adherence to HAART and engagement in care lower in their hierarchy of needs.

Income and financial assistance. At the time research interviews were undertaken, no participant was employed. Most relied on government financial assistance which provided less than 15,000 dollars annually, a sum which has been associated with suboptimal adherence in BC (O'Neil et al., 2012). One participant who received long-term disability insurance from a former employer described an annual income of more than 15,000 dollars.

Um, like I said I was lucky because I get an honorarium, or not an honorarium, long term insurance, and it's pretty good. It's a little under two grand a month, so I can live all right on that, no problem at all. But you know like I said, I know a lot of other people that get 900 dollars a month, or 800 dollars a month and try to live on it. And if I was in that boat it would probably be a little bit harder (Client, Interview 2).

Two participants commented on receiving honoraria from a CBAO or other social service organizations, or research project participation as being important sources of income. One of these participants felt she was financially reliant on these honoraria.

We get um, gift certificate for food every three, six months and it's for 25 dollars. And we get bus tickets here (CBAO). In the wintertime they provide socks and mittens and tuques, um they have a client meeting every Friday and they serve lunch for everybody, all the clients here. Um, (CBAO member group), they have presentations they give and

they get paid for that. This place (*CBAO*), financially we depend on it (Client, Interview 7).

Two participants described challenges with accessing other financial supports related to health care needs. One participant described her frustration with trying to access funding for a nutritional supplement from a financial aid office and eventually gave up trying to get it.

Well I have taken in prescriptions to the welfare and I have dropped them off and that's a prescription stating how much pill, or, or how much boost for how long it's gonna last me and how much it's gonna cost, everything is on this piece of paper you know, so that they can't say that 'oh this wasn't brought to them, or that wasn't brought to them' it was all done by the pharmacist and everything, legal tender, typed and whatever, and each time it's like, I don't know where their carpet starts in there, but it got swept under the carpet and it's gone, three different times, so I gave up, and they still want me drinking this (*boost*) three times. Well I can't (Client, Interview 6).

Another participant described the hassle and long wait on the phone when trying to get funding for a health care related trip to Vancouver, and having to postpone an appointment with a specialist because the financial assistance had not been approved in time.

One day I started at 7:30 in the morning for four days straight until 4:30 in the afternoon and could not get through, and that's just so discouraging, like so... especially when you're already stressed out and you're thinking about all these things that you have to do and then you can't get through to these guys and you've got everything planned out and where you have to be at what certain times and all that and then it couldn't get done. I'm like uhh. And like sometimes I'm like I'm just not gonna go then, which doesn't do me

any good, doesn't do the doctor any good. So yeah, there's been a few times that I cancelled and just given up cause I was so stressed out (Client, Interview 4).

The experiences of participants living on a low income shed some light on the variety of ways that having a low income can impact one's treatment with HAART. As previously discussed having a low income is a primary factor in unstable or inadequate housing conditions and food insecurity. Having a low income also creates the need to access supplemental funding for a variety of health care needs. The difficulties described by participants in accessing these supplemental funds points to a fragmented and bureaucratic nature of these services. It appears that participants face significant barriers in securing access to these funds, and this is especially problematic for those less capable of advocating for themselves. Therefore, the barriers to accessing supplemental funding for health care needs can be a direct barrier to the quality of one's treatment with HAART in terms of access to care.

Having a low income creates multiple challenges resulting in situations of chronic stress caused by relative, and in many cases, absolute poverty (Wilkinson, 2005). The difficulty in accessing basic needs and the ways in which poverty circumscribes one's life resulting in less personal control makes adherence to HAART and engagement in care difficult for some to achieve. The government financial supports meant to ensure that those without enough money have supplemental funding in order to afford needed care and services are not provided in a way which meets the needs of all who require this funding. While people do access these funds many find it onerous and stressful, and may require extra support from advocates to do so.

Substance use. Reading and Wien (2009) classify health behaviours as a proximal social determinant of health. Participant comments as well as the academic literature indicate that use of drugs and alcohol are behaviours relevant to understanding issues of adherence to HAART

and engagement in care. Substance use, such as drug and alcohol abuse, has been linked to lower levels of adherence to HAART (O'Neil, et al., 2012; Parsons, et al., 2007). Participants' comments regarding their substance use also indicate that drug and alcohol use can contribute to missing doses of HAART for a variety of reasons, but this was not universally so. Several participants said that being under the influence of drugs or alcohol made them more likely to forget a dose. One participant feared interactions between alcohol and illicit drugs with her medications and would purposely miss taking her medications if she was drinking or using drugs.

I always think when I use, um under the influence it mixes with my medication, that's why I don't want to take it. Yeah. And then drugs too, you don't know, cause you don't know what sort of stuff they put in the drugs that you're taking eh. And it's cocaine and medications. They say it don't mix, so I, that's mostly why I don't take them. Same with alcohol (Client, Interview 7).

Another participant articulated how drugs and alcohol use was prioritized over taking medications, and that side effects, such as nausea, were sometimes reasons to not take HAART medications when under the influence of drugs or alcohol. This participant also commented that vomiting medications up was another reason doses would be missed, especially when using illicit drugs or alcohol.

Um, I would take it (ARV medications), but it would either come back up and I just think oh god if I take it again I'm gonna puke, so I'm, I was more worried about getting stoned at the time than my health, obviously, cause yeah. Cause yeah, basically committing slow suicide to yourself. But, yeah, um having to remember taking them, or taking them was

the biggest thing at first. But now that I've gotten in to a routine it's pretty, pretty good (Client, Interview 4).

One participant commented that her substance use was a way to cope with the stress of being HIV positive.

As, I'm not comfortable, I have to drink, I have to do drugs, I'm so embarrassed that I got a grandchild. I'm just closed in, I've been closed in for 15 years now, cause I'm pissed off with this. It's not our fault we got it (*HIV*), you know. But what made it come in this fucking god damn world (Client, Interview 1)?

All participants who said they had challenges with addiction to drugs and/or alcohol also commented on changes in their addictions over time. One service provider gave an example of the variable nature of addiction, and its impact on adherence to HAART.

Yeah, I just had a person that was having some personal challenges and is doing better now, and back on the meds, but it wasn't an intentional dropping off, it was just the addiction took over in one's life and suddenly looking after one's health and taking the meds goes way the bottom of your list of concerns and priorities (CBAO worker, Interview 11).

Participant comments suggest that addiction to drugs and alcohol can affect adherence to medications and engagement in care in both direct and indirect ways. Direct influences were already mentioned such as the greater likelihood of forgetting a dose, or purposely not mixing medications with drugs or alcohol. The indirect influence on adherence and engagement in care relates to how substance use can negatively impact one's supportive relationships or one's ability to maintain stable housing. An addiction can also reduce an already low income, and increase

stress. However, substance use should not be viewed only as a cause of barriers to adherence and engagement in care, but it also is a consequence of stressful, challenging and sometimes traumatic lives.

It should also be noted that not all participants who commented on using drugs or alcohol felt that their substance use impacted their adherence to HAART. Some reported high rates of adherence, or when asked about the reasons a dose might be missed commented on factors unrelated to drug or alcohol use. While it is possible that the impact of drug or alcohol use may be underreported by some, it is also possible that some with an addiction to drugs and/or alcohol can still achieve an optimal level of adherence and regular engagement with HIV-related care. It appears to be the intersection between one's substance use and the other relevant social determinants of health which create the most significant challenges for one to be adherent to medications and engaged in HIV-related care.

The proximal social determinants of health interact and influence one another and fundamentally contribute to a person's lived experience. The requirements of 95 % adherence to medications and continual engagement with health care can be onerous to anyone, but when challenges with housing, food security, stigma, and addictions are added, these requirements become even more onerous and difficult to achieve. The support from friends, family and organizations can help people achieve a high level of adherence and regular engagement with HIV-related health care, but for many the available supports are not enough.

HAART and the experiences of the intermediate social determinants of health

Examples of intermediate social determinants of health are “community infrastructure, resources, systems and capacities” (Reading and Wien 2009, p. 1). Emphasis here will be given

to a discussion on participants' interactions with the health care system including relationships with providers, experience of stigma within health care settings, access to care and medications, as well as participants' involvement with a local community-based AIDS organization.

Relationships with health care providers. The quality of the relationship between a patient and health care provider⁴ has been shown to impact the outcomes of treatment with HAART (Beach et al., 2006). Two studies investigating the common characteristics of excellent adherers to HAART found a high level of trust in a provider, and a strong patient-provider relationship were often present among excellent adherers to HAART (Lewis et al., 2006; Malcolm et al., 2003).

Participants in this study commented on a range of factors which affected their perception of their health care providers and their relationships with them. Factors which participants referenced as being positive qualities of health care providers included knowledge and experience with HIV care, taking the time to talk with patients, listening to patients, being available, taking action based on the patient concerns, and knowing the patient.

...and they're (*health care providers*) just really good, they're really good. They listen to you. Put it this way. I went and saw, I had an appointment with my (*health care provider*) last month in January, and the next day I had an appointment with the (*other health care provider*), and umm, umm, I liked to sort of follow up with them, because all my blood work goes to them and she looks at all of it, not just the CD4 count, viral load, but what's going on with everything. And when I saw (*health care provider*), I complained about

⁴ The term health care provider will be used in place of specific terms such as physician, nurse or pharmacist in cases where individual providers may be identified.

having sore legs and sore bones in my legs and he said umm, he said 'well you know it's a side effect you know you're going to have to go through it, blah, blah, blah, blah, don't go off the meds.' Don't get me wrong (*health care provider name*) is a good (*health care provider*). I told the same thing to (*other health care provider*) the next day and she ordered a bone scan. So, they're good (*health care providers*), and so is (*health care provider*) but you have to ask for this shit. You have to be your own (*health care provider*). Really (Client, Interview 2).

Yeah I see (*name*) yeah, he comes in and hunts me down to do my blood work. (laughs) He always knows where to find me. I see, it just seems when I go down to (*downtown clinic*) everybody wants to see me to try to get me to do blood work or something or they got a new vaccine or something like that. They think of something just to keep me there (laughs). I just laugh, I say you caught me now, now you're gonna make me stay here for more work eh (Client, Interview 7).

Participants also commented on what factors they described as negative qualities. These included disrespectful or rude treatment, a lack of HIV specific knowledge, feeling ignored or mistrusted by a health care provider, spending too little time with patients, or not being available when needed.

I used to go down and see (*health care provider's name*) , at ah, what do you call, (*a Vancouver hospital*) but now that they've got a (*health care provider*) here they want us to see this new (*health care provider*) here, but I don't, I went to see him one, the first time I met him and I was, I've had HIV for a long time and I read up on it and stuff, you know I'm pretty smart, I know, I know my body and what's going on and I was trying to

explain to him and he told me I was, I didn't know, shut my fucking mouth you don't know what you're talking about (Client, Interview 8).

It's hard to find a good (*health care provider*) cause I feel like they ignore me, so I don't go in until I'm really, really sick... yeah. No I don't have a proper (*health care provider*) yet (Client, Interview 1).

While there is much evidence that suggests the quality of the patient-provider relationship does impact adherence to HAART, participants in this study typically did not associate a poor patient-provider relationship as being a reason for reduced adherence. However, participants' engagement in care does appear to be influenced by the quality of the patient provider relationship. Participants who reported poor patient-provider relationships reported less engagement in care such as only seeing health care providers if they felt seriously ill, or not seeing particular health care providers at all. Also, participants commented on having a number of health care providers including primary care physicians, specialist physicians, nurses and pharmacists and, as would be expected, participant perceptions of the quality of their relationships with different providers ranged from good to poor. Participants usually reported having better relationships with providers they saw more regularly, and who did outreach work. The varied influence of multiple providers adds to the complexity of understanding the role of each patient-provider relationship in ones' adherence to HAART and engagement with HIV related health care. As there are multiple providers working with patients the physician-patient relationship, which is most often discussed in terms of the impact on adherence, may not be the most critical relationship for patients in terms of their adherence to HAART or their engagement HIV-related care.

Another factor which appears to affect the quality of the patient-provider relationship is a patient's history of drug use. Research by Bakken, et al. (2000) found that those with a past history of injection drug use had lower levels of engagement with health care providers as well as lower levels of satisfaction with providers. Participants in this study who had histories of illicit drug use expressed a range of feelings about their relationships with health care providers, and therefore evidence from this study supports a conclusion that drug and/or alcohol use by a patient does not necessarily create a strain in the patient-provider relationship, but it can. One participant in this study expressed feelings of frustration that physicians would not prescribe pain medications because they did not trust patients with those medications.

Yeah, cause lots of the doctors they think that if they (*patients*) ask for pills, certain kinds of pills they won't give them cause they think they'd only try to sell them eh, but that's not the case. I don't know I guess it's called like better respect for, for the patients (Client, Interview 7).

If a patient feels certain medications are being withheld due to a physician's lack of trust in that patient, then a conflict may arise creating a strain in the patient-provider relationship. This strain may then affect a patient's adherence, or level of engagement in care.

There also were structural factors which appeared to affect the quality of participant's relationships with their health care providers. Several participants reported frustrations with rarely seeing the same physician, having difficulties getting an appointment without a long wait, and feeling rushed in appointments with physicians. These factors certainly can create a barrier to the establishment of a good patient-provider relationship.

Yeah, there's like 3 or 4 different doctors in there, so you're not just dealing with one

doctor that you know and then you gotta know what's going on and everything and then all of a sudden I'll make an appointment to see a doctor and then I'll end up seeing somebody else and they don't know what the hell's, you know it's like holy fuck, it's just stupid, sorry for my language (Client, Interview 8).

You know I just go in there and, you know, like the they just, you know, they just don't seems like they, you know, they got so many patients, you know, so much you know, they just wanna get in and out you know. Yeah, rushed and, yeah (Client, Interview 3).

Um, see that's a very touchy subject (laughs). Um, I don't wanna say anything one way or the other because I tell you, they do, do one hell of a job, um, considering the amount of people that they have to um, service, (*primary care clinic*) um, they need to be given a pat on the back rather than a kick in the ass, ok, um, but yes we need more doctors, other than that, um, somebody checking like a dietician or something would be nice (Client, Interview 6).

The various factors which affect the quality of the patient-provider relationship are in part dependent on the characteristics of a provider, but as the above quotations reveal can also be affected by structural factors. For example, the amount of time a provider spends with a patient appears to be an important factor in a patient's perception of the quality of the patient-provider relationship, as well as having consistency in which provider is seen. Several participants expressed their frustrations in not being able to see a physician as often as they felt was necessary and associated this problem with too few physicians and too many patients. These issues illustrate the link between the quality of patient-provider relationships with funding and

priorities within the health care system which impact the availability and work loads of providers.

Side effects and co-morbidities: complicating care and decreasing quality of life. For many participants the experience of side effects and co-morbidities created significant challenges and hardship. However, none of the participants said they would purposefully skip a dose of HAART due to its side effects.⁵ For many participants the experience of co-morbidities and side effects impacted their lives daily, and influenced their interactions with health care providers.

Cause I don't like feeling drowsy cause I just feel like laying down, sleeping all day and I can't do anything if I'm sleeping all day. And if I'm tired I get grouchy and nobody wants to see a grouch. And I gotta deal with people every day and get out and do something. Cause if I don't do something then I'm just stuck in my addiction. That's why I like keeping busy (Client, Interview 7).

A comment from a CBAO provider articulated that side effects when added to other significant life challenges can reduce adherence to HAART.

...when you have multiple issues already whether it's a mental health issue, or addiction issue, or both issues, or I think you know when you have, it, you don't wanna have another issue on top of it. You don't want to have to deal with the side effects of medication as well, on top of it, and um, so that's a big, so that's a big, part of a big

⁵ One participant cited missing doses due to vomiting after taking medications, and one participant commented on missing doses due to a fear of how medications would interact with drugs or alcohol, but no participant commented on consciously choosing not to take a dose of ARV medication to reduce a side effect.

reason that people aren't as adherent on their medications as they could be (CBAO worker, Interview 9).

This comment indicates that it is the added burden from side effects to an already challenging life that creates a circumstance where side effects lead to reduced adherence to HAART. It seems plausible that when an individual faces a multitude of stresses in life he or she is less able to cope with the impact of these side effects.

There was also a large proportion of participants who had co-morbidities including hepatitis C and arthritis. Co-morbidities and side effects appear to impact an individual's interaction with the health care system through the need for greater engagement in medical care, more complex health care needs, and the potential requirement of greater provider expertise, such as specialist care. Two participants commented on having a co-morbidity which affected their mobility, and one cited the limited mobility as a reason for missed doses of ARV medication. Co-morbidities also may require one to take more medications adding to the pill burden. Several participants commented that they have a large number of pills to take beyond their ARVs. Even though ARV pill burden has decreased over time the presence of co-morbidities increases the pill burden for many. Also, as the population of people living with HIV ages the presence of co-morbidities and long term side effects will only increase. The overall effect of co-morbidities and side effects is that greater health management is required which often means greater pill burden, a need for greater engagement with health care services and a potential reduction in one's health-related quality of life, all of which increase the challenge of adherence to HAART and other medications, and engagement in care.

Stigma in a health care setting. This section discusses participant experiences of stigma and discrimination within health care settings. Experiences of stigma and discrimination were most often reported when receiving care from health care providers, or other staff, who were not regularly providing health care services to participants. These experiences most often took place within a hospital. These experiences of stigma and discrimination within a health care setting, while potentially less overt than experiences of stigma and discrimination in the community, can have a direct and detrimental effect on patients' HIV- related health care. Results discussed in this section are not limited to HIV-related stigma, but any perceived reason for stigmatizing or discriminatory behaviours.

Almost all participants described having experienced feeling stigmatized or discriminated against in a health care setting at some time. Generally, participants have cited experiences of discrimination in a hospital which was most often attributed to stigma based on drug and/or alcohol use rather than HIV status, but participants also commented on experiences of HIV-related stigma. Participants described being treated poorly; not feeling as though they were being treated as a person, and feeling discriminated against because of their Aboriginal ancestry.

Well they see (*health care providers in a hospital*), they see all the scars on your arm and everything like you're an ex druggie or whatever and they just treat you like shit. Bad (Client, Interview 8).

Most of us do not like going to the hospital. Um, because the first thing you run into is the emergency room. And right away that's where prejudice comes in. Um, people should be more closed mind about um, their, their prejudices or whatever with um, um, like all they look at me when they see is there must be a flag in my file stating that I was an IV

drug user. Because, that's all that they seem to see...Um, is because so many of the care givers um, see that they only see the IV drug user, they don't see the person that's a person. Because I am a person and yes, once upon a time I did have an IV needle in my arm every ten minutes, that was my way of life, but um, if I wanna live now, I, I can't drink and do drugs, um, because it, my (*ARV medication*) wouldn't be working... (Client, Interview 6).

Like the experiences of stigma at a community level, the experiences of stigma and discrimination at a health care setting contribute to feelings of stress, anxiety and may contribute to depressive symptoms, which are associated with lower levels of adherence (Venable et al., 2006). What makes these experiences particularly harmful is that they reduce the quality of care and can directly impact access to health care as some participants commented on refusing to seek treatment at the hospital unless absolutely necessary.

However, experiences of stigma in a health care setting do not appear to impact participants' views of all health care providers as all participants commented positively about at least one health care provider who was involved in their care. The good quality patient-provider relationships that participants had with other providers appeared to act as a buffer against some of the potential harms of experiencing stigma in a health care setting such as disengagement with care, or non-adherence due to a lack of provider trust. However, for people whose only contact with health care providers often results in stigmatizing experiences it is reasonable to speculate that the stigma and discrimination experienced in any health care setting will be a significant barrier to engaging with HIV-related health care.

Since many of the experiences of stigma took place within a hospital it is possible that participants' views of hospital-based health care service is poor, which, for some, affects their choices in accessing needed services, such as addiction treatment programs like detoxification, routine diagnostic services, or emergency care. Thus, the impact of experiences of stigma within a hospital may have far reaching consequences which may ultimately reduce the health care resources available to people living with HIV.

Accessibility of antiretroviral medications. The method of ARV⁶ medication delivery is an important component of access and adherence to these medications. The methods of ARV pill pick-up for participants ranged from daily pick up at a pharmacy which was coupled with methadone maintenance therapy (MMT) (3 participants), picking up a supply of ARV's from the participant's doctor's office (4 participants), or having a weekly supply of medications delivered by a pharmacy (1 participant). Participants' varied in their satisfaction with the methods of medication delivery.

One participant cited missing a dose of his ARVs 3 or 4 times a month due to a co-morbidity affecting his mobility which created difficulty in getting to the pharmacy to pick up his daily dosage of methadone and ARVs. Although this participant expressed a desire to have a supply of his ARVs at home he also acknowledged that picking up his ARVs with his methadone made it less likely that he would forget to take the ARVs.

⁶ Antiretrovirals (ARVs) refers to the pills which comprise antiretroviral therapy, or HAART.

I don't know why the doctors did it this way, but it's fucking really hard for me to get down there to get my methadone, and I, I get it (ARVs) every day in blister pack at the pharmacy, but I gotta go down there and get it (Client, Interview 8).

But sometimes too I'd be so st... I'd forget, so it's a little bit better, at least I know that I'd be getting it every day, and I wouldn't forget, when I do it that way, but it's just getting down there and back home (Client, Interview 8).

Another participant who also received her ARVs coupled with methadone on a daily basis discussed her frustrations with feeling as though she was tied to the pharmacy. She also commented on how being on MMT aided her adherence to HAART by ensuring she would not forget a dose.

Um, it's not fun at all. Um, to be on, um, how can I say this, it's not fun at all to be ball and chained to a, the drug store, but um, I am. My life is, um, there's, I can't do anything in life until I go to the doctors and I go through um, the ropes of getting my methadone and um, my (*ARV medication*) because of the fact that methadone is a man-made heroin. And so, I'm not just taking it, I'm wired to it, and that to me, I don't believe in (Client, Interview 6).

Another participant on MMT discussed how she would forget her ARVs on Sundays when she would get a carry⁷ from the pharmacy. This problem was remedied by text message reminders from a nurse.

⁷ A carry is when a dose of medication, in this case a dose of methadone, is given to a patient to take home.

Although the daily pick up of ARVs along with methadone at a local pharmacy did create challenges, these findings do suggest, as participants acknowledged themselves, that being enrolled in MMT improved adherence to ARVs by reducing the chance of forgetting a dose. These findings correspond to research which found increased adherence to HAART and improved treatment outcomes among people receiving MMT (Palepu, et al., 2006). Research also has shown an increase in adherence to ARVs when patients are enrolled in a directly observed treatment programme (Tyndall, et al., 2007). While participants of this study had directly observed treatment for ARVs only because these were coupled with directly observed MMT, an increase in adherence to ARVs is likely a combination of increased stability from MMT, and daily observed doses of ARVs. However, the feelings of being tied to a pharmacy expressed by one participant, and the mobility challenges of another, indicates the drawbacks to daily witnessed MMT and for some these may create significant barriers to beginning and maintaining treatment with MMT and HAART.

Three of the four participants who picked up a supply of their ARVs from their doctor's office reported high levels of adherence, and did not report missed doses due to the method of medication pick-up. However, one participant commented on difficulties with the process of re-ordering HAART where one is required to call the provincial pharmacy based in Vancouver which supplies HAART two weeks prior to needing a refill of her prescription.

And with like having to go to your doctor and see the pharmacy and phone it in and just the um, a lot of that with, with people on drugs and drinking and stuff I think is a big, um hassle, of having to remember the two week thing (Client, Interview 4).

This process caused her anxiety because she feared she would forget to call, and not be able to get her medications without missing a dose. This participant's comment also indicates

that she felt people with active addictions would find this process too onerous. The anxiety felt by this participant likely increased her overall level of stress, but also demonstrated an understanding of the importance of a high degree of adherence. Increasing the support available for the process of ordering ARVs, and having access to a contingency supply, will likely benefit those who may find the process particularly challenging, and reduce the stress for those who fear missing doses because of forgetting to order their ARVs.

Involvement with a community-based AIDS organization. The supports provided through a CBAO are similar in character to the social supports discussed as a proximal social determinant of health. However, the existence of a CBAO is a feature of a community's infrastructure, and relies on funding primarily from government agencies. Therefore the impact of a CBAO on adherence to HAART and engagement in HIV-related care will be presented as an intermediate social determinant of health.

All participants were recruited through a local CBAO, and therefore had some level of involvement with this organization. The majority of participants expressed that having a CBAO was an important resource to them, and benefited their well-being in a number of ways. Key themes of participants' involvement with a CBAO were the sense of community and emotional support, opportunities for education about HIV and HIV treatment, and tangible supports, such as honorariums, food support, rides, and advocacy with social and health care services. These supports appear to aid adherence to HAART, as well as engagement with health care in a variety of ways.

The sense of community and emotional supports offered by and accessed through a CBAO appear to play an important role in participants' ability to accept their HIV status and to

mitigate some damage from experiences of stigma and discrimination. The emotional support offered by staff and peers also appears to play a role in participants' sense of well-being and might reduce depressive symptoms, and thereby support adherence. One participant described the CBAO as being the only place to meet other people living with HIV.

You'd never see any HIV, you'd never meet any HIV people because nobody says anything about it right. The only place that you find HIV people, really is here, if you wanna go looking for them unless you know them already. So, yeah, here is where you have to be if you want to meet other, if you want to see other HIV people, or be around them or whatever it is you need there (Client, Interview 2).

One participant described her close relationship to CBAO staff as well as the comfortable and welcoming environment. This participant, as well as others, also commented on the sense of fulfilment from being able to help others who are living with HIV, and it appears that these relationships are often facilitated by a CBAO.

Just how, they're (*CBAO staff*) not like, some places you go, they're, they act like they know what they're doing, or into, and it's just fake, whereas here it's like a friendship based type of thing, and um you can, if you want you can just go to sleep on the couch, or like hang around all day, or um, just and doing these things, like research things and stuff like that I find is a plus, and um, lots of um, yeah just helping people out, and stuff (Client, Interview 4).

Education and an increased level of HIV-related health literacy was another common theme participants referenced as a benefit of their involvement with a CBAO.

And I ran into a guy named (*name*), and his CD4 count had been 30 and his viral load had actually been over 1 million at one time, like months and months previous to that and now his CD4 count was a little over 200, his viral load was undetectable, and he said ‘oh yeah it’ll work for you too. Just pay attention and learn and do what the doctors tell you.’ And I can tell you that it was like a weight came off me, like, are you kidding me, like, I mean I thought I was, you know, I thought I was heading for the grave. You know, so as far as your question is concerned, um, other, one of the best sources of information are other people who have been through it, um for a number of years, and know what they’re talking about (Client, Interview 2).

Um, well, being, being a member of the (*CBAO member group*), um, my whole life revolves around it basically. So, um, it’s almost like I eat, sleep and shit, excuse me (laughs) you know, the, the whole HIV prevention, and, and, and, that if I wanna learn something it’s there. Because I’m right in it (Client, Interview 6).

Participants also commented on the tangible supports they received from CBAOs such as rides, food, and advocacy for health and social services. These supports clearly aid one’s engagement in HIV-related health care when CBAO staff provide transportation or accompany members to medical visits. This is particularly relevant in Smithers where CBAO staff can drive members to Prince George for specialist appointments necessary to begin HAART. CBAO supports also help provide basic needs, and reduce the stressors participants may experience in terms of food security, accessing social services, and dealing with housing issues.

The benefits participants receive from a CBAO can affect adherence and engagement with health care through a variety of mechanisms. Social and emotional supports likely reduce stressors and

depressive symptoms and increase one's sense of the quality of life. Educational supports can improve adherence and provide information about how to manage side effects, or the availability of health care related resources. Finally, the tangible supports provided by the CBAO can both directly and indirectly support adherence to HAART and engagement in HIV-related care through supports which provide basic needs, such as a food hamper, and increase accessibility to HIV-related health care.

Geographic Analysis

One of the goals of this research was to identify differences in participant experiences of being on HAART in Smithers and Prince George, BC. While further research is necessary to get a clearer picture of how being on HAART differs in these two communities, there are some clear differences in the identified barriers and supports to adherence to HAART and engagement in HIV-related care.

The majority of participants were interviewed in Prince George, and were residing in this city at the time of interviews. There were several factors relevant to creating barriers or supports to adherence to HAART and engagement in HIV-related care which appeared to differ between Smithers and Prince George. Participants in Smithers stressed the role of the lack of affordable and supported housing in the community. One emergency shelter exists, but the length of time one is permitted to stay is limited. Cheaper housing options exist in neighboring towns, but these communities have fewer social and health care services available and there is a lack of public transportation between towns. Also, participants commented on their observation that alcoholism created a greater barrier to beginning and maintaining treatment with HAART than did injection drug use. Differences in population patterns of substance use between Prince

George and Smithers may exist, but it may also be that because fewer services exist in Smithers the impact of substance use on adherence and engagement in HIV-related care is greater.

CBAO staff participants as well as participants who had been prescribed HAART in Smithers described a greater sense of HIV-related stigma and difficulties in keeping one's status confidential than did participants in Prince George. A greater sense of stigma is possibly related to less privacy and anonymity in a smaller community, but may also be affected by the smaller number of people living with HIV. There may also be a greater level of misunderstanding and misinformation about HIV in a smaller community, leading to greater HIV-related stigma.

Participants in Prince George commented more readily about their frustrations with getting appointments to see a physician than did participants in Smithers, and participants in Smithers commented more positively regarding their relationships with physicians than did participants in Prince George. In both communities most participants commented on experiencing stigma in a health care setting which took place in a hospital, rather than a clinic. Both participants on HAART who were interviewed in Smithers made trips to Vancouver for specialist care, while participants in Prince George either did not see a specialist, or saw a specialist locally. CBAO staff interviewed in Smithers commented that members will travel to either Vancouver or Prince George to receive specialist care, and that this necessary travel created significant barriers to engagement in HIV-related care for some people.

It is not surprising that stigma, problems with confidentiality, and fewer social and health care resources are described as being more significant issues in Smithers as these are commonly identified characteristics of rural communities. The greater impact of alcohol use on adherence as reported in Smithers may also be an important feature of how Smithers and Prince George

differ in terms of the barriers to adherence to HAART and engagement in care. The presence of a CBAO and health care providers who have good relationships with participants is a feature present in both communities which appears to significantly support adherence and engagement in care. Only one CBAO exists in northern BC and at the time of research interviews, this CBAO had offices located only in Prince George and Smithers, but provided education and support to communities throughout the region.

It should be noted that there is likely great variability in rural communities in northern BC, and that only 4 participants in total were interviewed in Smithers. More research in other rural communities and with more participants will be necessary to better characterize the extent and nature of peoples' barriers to adherence and engagement in care in rural areas of northern BC. It is likely that those living in communities without the services of a CBAO experience greater challenges living with HIV.

Aboriginal ancestry

The majority (6 of 8) of participants interviewed who had been prescribed HAART identified as being Aboriginal, or of having both Aboriginal and European ancestry. Participant comments relating to how being Aboriginal affected their HIV treatment or care varied. Most reported that being Aboriginal did not impact the quality of the HIV-related health care they received although one participant commented on feeling discriminated against in the hospital because of her Aboriginal identity.

They label Native people up there and it shouldn't be that way. Everybody's treated equally and not everybody's a drunk or a drug addict up there (*in the hospital*) (Client, Interview 7).

Two participants who identified as having both Aboriginal and European ancestry linked their lack of Aboriginal status under the Indian Act to having fewer supports.

It's really hard for me cause I ain't status. First thing they (*financial assistance staff*) ask, 'you status?' um, no, 'well we can't really, we don't know what to say' (Client, Interview 8).

One participant also spoke of the sense of community and pride she felt being an Aboriginal woman.

Oh, um, my background being Native, um I think everybody sees that, um, I have a lot of friends that are Native, and they are starting to look up to me now, the younger ones, in town, I like it when they call me auntie or cuz, you know like mom or something like that, um, they, other Native people that are complete strangers, they acknowledge me eh, like they say hi to me on the street and I say hi, and then I get, I get this rush of happiness through my, myself eh. I'm really proud to be a Native (Client, Interview 7).

One participant, when asked about how she felt being an Aboriginal woman affected her HIV treatment, responded with a discussion on survival when both her gender and ancestry were described as 'strikes against' her.

Oh ok. If you wanna know about being an Aboriginal woman. OK. Um, there is still a hidden rule that I've learned to live by and that is we've got three strikes against us, being Aboriginal women. But give it some time and times are gonna change. But number one, we're a woman, number two, we're Aboriginal, number three I've got brains, but, don't ever show that third one. Because, that thing scares people off quicker than finding out, they can handle two of the three, but three out of three, when it comes to brains, mm mm,

you keep them well hidden and you put a mask on, right, you only let certain people know you've got a brain inside that head because it can, it can really break ya. Yeah. It can (Client, Interview 6).

One participant linked her mistrust of some health care providers to the lasting impact of the residential school system, and felt that an Aboriginal physician would allow her to be more comfortable with seeking care.

...we need somebody (*a physician*) who's been around our region. Um, sort of like a traditional territorial kind of guy, or girl, for a doctor. Then we'll feel comfortable because us urban people we're so far away from home that, um, just the past residential school era we don't trust anyone... (Client, Interview 1).

Participants who identified as being Aboriginal discussed to a greater extent their experiences of discrimination based on race, or a perception of drug or alcohol use, and participants who identified as having Aboriginal ancestry commented to a greater extent on having poor relationships with some health care providers. Aboriginal ancestry was also discussed by some in terms of a sense of community, pride and spirituality.

None of the participants identified the use of traditional healing practices to complement the medical treatment with HAART. However, it is possible that traditional healing practices were used by participants, but for reasons other than complementing their HIV care, and therefore the participants may not have associated these practices with their HIV treatment. Also, some researchers have suggested investigating cultural barriers to adherence among Aboriginal people on HAART (Martin et al., 2010). None of the participants who identified as being Aboriginal commented on any experiences of barriers to adherence related to Aboriginal

culture, but commented primarily on barriers related to socioeconomic status, stigma and social isolation and substance use, just as non-Aboriginal participants who had challenges with adherence did as well.

Conclusion

This chapter presented the results of this qualitative study. Results were first organized in sections relating to proximal and intermediate social determinants of health. Results indicated that poverty, social exclusion, substance use, and inaccessibility of health care and social services created the greatest barriers for participants' to be adherent to HAART, and appropriately engaged in HIV-related care. Supports were positive relationships with friends, family, health care providers and CBAO staff, not having to worry about basic needs, such as food and housing, and having a method of accessing medications which met one's needs. A geographical analysis identified some differences and similarities of participants' experiences of HAART in Smithers and Prince George. Barriers unique to Smithers were the need to travel for specialist care, fewer housing options, less anonymity and a greater sense of HIV-related stigma within the community. Results were then presented which addressed participants' comments on how their Aboriginal ancestry affected their experience of HAART. Participants identifying as Aboriginal discussed a range of ways that their ancestry played a role in their HIV treatment. Some participants commented on issues related to racism and colonialism which affected the quality of their health care. Some commented on their pride in their Aboriginal ancestry and a strong sense of community.

The various factors discussed in this chapter play a huge role in determining how challenging it is for an individual to be adherent to HAART and engaged in HIV-related care. These factors act in complex ways and should not be understood as isolated, or static, but

dynamic and interconnected: these factors intersect with one another and shape participants' individual experiences of HAART. These results are also focused on the lived experience of participants and participant comments rarely explicitly addressed the distal social determinants of health. The following chapter will reference relevant research and discuss the ways that my own findings align with, or diverge from, the current academic literature on HIV treatment and link participant comments to some distal social determinants of health.

Chapter 5: Discussion

This study set out to identify and describe the barriers and supports to adherence to ARV medications and engagement with HIV-related care based on participants' experiences of being on HAART. An interpretive phenomenological methodology was employed with face to face interviews being the method of data collection. In this chapter I will outline some of the main findings of this research, and then I will discuss how these findings relate to or depart from previously published research findings. An orienting framework which consisted of a social determinants of health model, a biosocial approach to adherence, and the concept of structural violence, guided the interpretation and presentation of the results. As with the previous chapter, the organization of this discussion will start with factors relating to the proximal social determinants of health, then the intermediate determinants, and then a discussion on the geographical factors, and Aboriginal ancestry. This chapter will continue with a discussion on the distal social determinants of health and structural violence, and end with a discussion on three primary themes which propose generally how barriers and supports to adherence and engagement in care function.

Proximal Determinants

Social supports. Social support appears to be linked to greater adherence to HAART and engagement in HIV related health care. Participants' comments touched on a variety of ways in which family, friends and partners provided emotional, material and informational supports. These supportive relationships likely impacted participants' sense of well-being and quality of life, supported access to health care, medications and to basic needs, such as food and housing.

These findings are supported by research which addresses the link between social relationships and adherence to HAART. In a cross-sectional study of 90 men and women in the United States Gonzalez et al., (2004) reported social support was positively associated with adherence to HAART which was partially mediated by a positive state of mind, which the authors claim is a measure of “overall positive mood and life satisfaction” (p. 414). Gonzalez et al., (2004) cite Cohen and Syme (1985) who suggested that social support mediates adherence because it provided patients with a sense of stability, predictability and control which supported a positive state of mind, and a decrease in depressive symptoms.

Similarly, a longitudinal investigation of 136 participants in New York by Simoni, Frick and Huang (2006) reported a positive association between social support and participants’ self-efficacy to adhere, which corresponded to participant’s self-reported adherence and was verified by viral load measures. These authors found that self-efficacy to adhere was not directly affected by social support, but that social support increased spirituality and decreased depressive symptomatology, anxiety and stress which then in turn lead to increased adherence to HAART (Simoni, Frick & Huang, 2006). Therefore these authors propose that social support indirectly affects adherence through a mechanism similar to that described by Gonzalez et al. (2004) as supporting a positive state of mind.

Power et al. (2003) reported a positive association between participants’ perceived satisfaction with social support from a partner with their level of adherence to HAART. However, this study’s findings differ from the literature in that it did not find an association between participant adherence and the satisfaction of perceived social support from friends or family. The authors speculated that the greater intimacy in a relationship with a partner and

closer proximity with a partner are reasons why the quality of a relationship with a partner has a greater impact on adherence to HAART.

These studies all contribute to the view that a positive social relationship can support a positive state of mind, or a decrease in depressive symptoms, which in turn can support adherence to HAART. Social supports can provide a sense of well-being simply from the nature of the relationship, but the material support they provide is also likely a factor in supporting adherence to HAART, especially for those living on a low or very low income. Material supports could include sharing living expenses with a partner, couch surfing, gifts of food or rides to medical appointments, all of which can support adherence to HAART and engagement in HIV-related health care in direct and indirect ways.

Stigma and discrimination. All participants reported having experienced HIV-related stigma. These experiences of stigma ranged from noticeable unease to exclusion from family. The findings of this research are compatible with the literature on HIV-related stigma in that it can be a significant stressor for people living with HIV, and that it can reduce one's quality of life and can negatively impact adherence to HAART and engagement in HIV-related care (Nyblade et al., 2009). However, there appear to be several factors influencing a person's exposure to, and impact of, HIV-related stigma.

Vanable et al. (2006) found an association between experiences of stigma and reduced adherence, and postulated that the mechanism of action may be a reduced enthusiasm for adherence and engagement in health care as well as a fear of being outed as HIV positive when taking medications or seeking HIV-related health care. Another mechanism postulated by

Vanable et al. (2006) was an association of experiences of stigma with depressed mood and reduced social support which these authors then linked to reduced adherence.

Lee, Kochman and Sikkema (2002) analyzed the association of a persons' level of internalized HIV-related stigma with other characteristics. They found that people who had high levels of internalized HIV-related stigma were more likely to have families who were less accepting of their illness; were less likely to have attended an HIV support group; were more likely to have higher levels of depression, anxiety, and hopelessness; had lower perceptions of social support; and were more likely to utilize negative coping strategies (Lee, Kochman & Sikkema, 2002). All these factors create barriers to adherence to HAART and engagement in care.

Clearly experiences and perceptions of stigma can have negative consequences, but not all are equally vulnerable to the negative consequences. Vanable et al. (2006) and Lee, Kockman and Sikkema (2002) described experience and perceptions of stigma as affecting adherence at least partially through greater depressive symptoms, and lower levels of social supports. It seems likely that those who experience significant stressors in their lives beyond stigma and those who may be socially isolated will be more negatively affected by a stigmatizing experience.

Research has discussed how one's vulnerability to experiences of stigma can be mediated by one's experiences of marginalization (Ware, Wyatt & Tugenburg, 2006). Ware, Wyatt and Tugenburg (2006) address these connections in a qualitative study of 52 people living with HIV who use illegal drugs. The authors of this study linked the social marginalization experienced by their participants to a greater desire for social connection which resulted in an increased fear of

disclosing their status and being stigmatized (Ware, Wyatt & Tugenburg, 2006). To avoid disclosure of their HIV status, participants described missing doses of HAART if there was a chance another person would see them taking the pills (Ware, Wyatt & Tugenburg, 2006). The authors postulate that living in marginalized circumstances creates a greater sense of loneliness and a desire to build relationships, which then leads to a greater fear of stigma and prioritizing of relationships over adherence to HAART.

Results from my own research also point to the possibility that one's ability to avoid stigmatizing experiences may also be mediated by one's socioeconomic status. Participants with greater socioeconomic status were more able to choose their environments and who they associated with. Participants' with a lower socioeconomic status were more likely to live in a shelter or supported housing, or have shared housing, and relied on food hampers and soup kitchens for food. However, this association was not found in the literature on HIV-related stigma. Further research would need to verify if low socioeconomic status reduces the ability for one to control one's social environment which in turn increases the risk of a stigmatizing experience.

Disclosure of HIV status. HIV-related stigma added stress to participants' lives and the fear of stigma added to the difficulty of both disclosing, and keeping one's HIV status private. A few participants described feeling great stress and anxiety in trying to keep their HIV status private. Participants also reported both positive and negative responses to disclosing their HIV status. By disclosing their HIV status, some participants reported having more social and emotional support from friends and family, but some also reported experiences of stigma and social isolation. These findings are similar other reported responses to HIV disclosure (Gore-Felton et al., 2008; Parsons et al., 2004).

While studies typically investigating HIV disclosure look to associations with HIV transmission risk behaviours, HIV disclosure is also relevant to issues of adherence and engagement in care. For one, the possibility of accessing more social supports because of HIV disclosure could support adherence. Negative consequences of HIV disclosure could detrimentally impact adherence or engagement in care. In a cross sectional study of 156 people living with HIV in California an association was identified between feeling regret after disclosure of HIV and being depressed (Gore-Felton et al., 2008). While this study did not specifically address adherence, or engagement in care the association between depressive symptoms and reduced adherence has been made (Simoni, Frick & Huang, 2006).

Several key aspects of the impacts of HIV disclosure appear to be missing from the literature. Disclosure is potentially helpful or harmful, and being able to identify what factors contribute to the consequences of disclosure would provide important insight in to supporting people living with HIV. Participants identified added support from their disclosure, but also greater potential for experiencing HIV-related stigma. Also, there was no literature found on factors associated with the stress associated with attempting to keep one's HIV status private. As one participant pointed out, her openness about her HIV status relieved the stress of trying to conceal it, but potentially increased the risk of experiencing of HIV-related stigma. It appears as though issues of disclosure are particularly relevant in smaller communities as maintaining confidentiality regarding one's HIV status can be a greater challenge.

Housing. Participants in this study lived in various housing situations and those who currently or previously had lived in unstable or inadequate housing situations commented directly on how their housing situation impacts their well-being. The academic literature points clearly to the negative impact unstable housing has on the well-being of those living with HIV

(Kidder et al., 2007). Unstable housing creates challenges to adherence, and is associated with higher viral loads as well as riskier behaviours (Hawk & Davis, 2012; Kim et al., 2009). Kidder et al. (2007) also found that homelessness was independently associated with HIV treatment outcomes after controlling for demographic and substance use variables, and postulated that access to care, prescribing practices of physicians and challenges to adherence are all potential explanations as to the lower health status of people living with HIV who were homeless.

What appears to be lacking in the literature on the effect of housing on adherence to HAART and engagement in HIV-related health care is an analysis of the various factors associated with housing which goes beyond a stable versus unstable housing dichotomy. Participants in this study identified a range of housing factors which they identified as being important to their well-being. Proximity to needed services and personal privacy appear to be two important housing factors which impact adherence and engagement with HIV-related care. For those who lived in shelters or supported housing, it is possible that a loss of autonomy creates stressors, however the availability of supported housing staff to support adherence to HAART is a clear benefit. Still, the findings presented in this thesis provide more insight in to a number of housing factors which may create barriers or supports to adherence and care, although more research will be needed to investigate this topic more thoroughly.

Food security. Many participants in this study were reliant on getting their food from food hampers or soup kitchens, which indicates a high level of food insecurity. The high prevalence of food insecurity among people living with HIV appears to be a common feature of the epidemic in Canada (Anema et al., 2011; Slater, 2012). The physical and emotional stress resulting from food insecurity was discussed by some participants. These findings correspond to

research which finds the consequences of food insecurity among people living with HIV have been shown to negatively impact physical and mental health states (Slater, 2012). Research in Vancouver BC found that those who were food insecure were twice as likely to experience depression (Anema et al., 2011). Food insecurity has also been linked to reduced adherence to HAART and can act as a barrier to health care access (Anema, et al., 2011; Slater, 2012). These findings are congruent with the results of this study which indicate increased stress and hardship among those who were food insecure.

Income and income assistance. Many of the barriers to adherence to HAART and engagement in HIV-related care seem to be rooted in poverty. All but one participant described having financial difficulties, and the one participant who felt his income was adequate earned less than two thirds of the average income for someone in Prince George or Smithers (BC Statistics, 2011). Most participants discussed difficulties in affording necessities such as food, clothing and shelter and depended on local agencies for material supports such as food, honorariums, and gifts of clothing. An income below 15,000 dollars annually has been associated with suboptimal levels of adherence in itself (O'Neil et al. 2012), and clearly a low-income will affect housing quality and stability as well as food security.

For some participants, their low-incomes required that supplemental financial supports be provided to cover some health care expenses. However, participants discussed feelings of frustration and stress when dealing with government agencies which provided financial assistance to the point where two participants said they just gave up in trying to access the financial supports they needed. These experiences unfortunately appear to be representative of a trend in Canada where financial supports and assistance programs have become increasingly

difficult for people to access, and have reduced the level of support provided (Chouinard & Crooks, 2008; Morrow, Hankivsky & Varcoe, 2004).

While the low income of many participants made it difficult to access basic needs, there is also an emotional toll which could impact one's adherence to HAART and engagement in care. In a longitudinal study addressing the impact of financial strain on participants' health, researchers proposed that financial strain and a reduction in one's sense of personal control led to depression, which then contributed to poorer health (Price, Choi & Vinokur, 2002). While this study by Price, Choi and Vinokur (2002) was not looking at adherence or engagement in HIV-related care the model proposed provides a potential pathway from financial strain from a low income to depression which then could negatively impact adherence and engagement in care.

Substance use. The primary mode of HIV transmission in northern BC is through sharing needles for injection drug use (Northern Health, 2010). It is not surprising then that a high proportion (7 of 8) of participants in this study who were living with HIV commented on having an addiction to drugs and/or alcohol. Participant comments indicated a number of ways in which substance use impacted adherence to HAART. Participants noted that forgetting to take their medications was more likely when using drugs or alcohol and that there were times when the use of drugs and alcohol had greater priority than taking medications. Milligan (2011) found similar responses among participants who use injection drugs in Prince George where "...changes in priorities, forgetfulness, and losing track of time" (p. 66) were the most common responses to how being high affected one's ability to adhere to HAART.

The literature clearly shows that the use of drugs is associated with lower levels of adherence to HAART and worse outcomes including faster disease progression and higher

mortality (Krüsi et al., 2010; Cook, et al., 2002). Alcohol use has also been associated with lower levels of adherence to HAART (Parsons, Rosof & Mustanski, 2007; Hendershot et al., 2009). However, not all participants in this study reported that their adherence to HAART was impacted by their drug use, and for those who felt their adherence was impacted, there was variability in the degree to which drug or alcohol use affected adherence. These findings echo research by Ware, Wyatt and Tugenberg (2005) qualitatively investigated adherence among 52 people actively engaged in using drugs. These authors found that while active drug use did impact adherence to HAART, the impact of drug use was often over-emphasized while the impact of non-drug-use-related obstacles was often underemphasized (Ware, Wyatt & Tugenberg, 2005). They pointed to common stereotypes of people who actively use illegal drugs which misrepresented the variability in peoples' use of drugs as well as the stability and control that some people can achieve while actively using drugs (Ware, Wyatt & Tugenberg, 2005). These findings add a layer of complexity to an understanding of the ways drug and alcohol use impact adherence to HAART, and do not allow simple interpretations of drug and alcohol use being the sole factors for suboptimal adherence.

A variety of contextual factors appeared to be at play in determining the degree to which an addiction to drugs and/or alcohol reduced one's adherence. Krüsi, Wood, Montaner and Kerr (2010) address the importance of these contextual factors by pointing out there is a need for a better understanding of the social and structural factors which impact the delivery of HAART to people who use injection drugs. The social and structural factors include the various proximal social determinants of health, discussed earlier, which comprise much of a person's lived experience. Stressors such as social exclusion, stigma, unstable housing or food insecurity can create stresses and anxieties which can negatively affect adherence. These stressors can also

contribute to the use of drugs and alcohol as coping strategies, which can also negatively affect adherence (Power et al., 2003). A cycle can continue as the use of drugs and alcohol can negatively impact one's ability to maintain stable housing, food security and quality social relationships, and therefore potentially creating greater challenges to adherence and engagement in care. When key components of the social determinants of health are available, such as stable housing, food and social supports, having an addiction to drugs and/or alcohol does not mean that a high level of adherence is unattainable, but when challenges with drug and/or alcohol addiction are concurrent with challenges in meeting basic needs then the requirements of a high level of adherence to HAART and engagement with HIV-related care become more difficult to achieve. It is the interplay between the effects of substance use and conditions of poverty and social marginalization which create the circumstances where adherence and engagement in HIV-related care are both challenging and could be viewed as a lower priority than other more pressing concerns.

Engagement in HIV-related health care also appears to be affected by drug use as research has shown that people who use injection drugs are less likely to ever begin HAART, and more likely to discontinue therapy (Krüsi, Wood, Montaner & Kerr, 2010). Bakken et al. (2000) found that those who used injection drugs were significantly less engaged in health care. My own findings indicate that the patient-provider relationship is negatively affected when a patient feels their substance use contributes to a physician's mistrust or lack of respect of the patient. It is plausible that a strained patient-provider relationship will make it more likely for a patient to miss appointments or to avoid health care, unless absolutely necessary, as suggested by participant responses. The effect of drug and/or alcohol use on the patient-provider relationship will be discussed in greater detail in the following section on the patient-provider relationship.

Intermediate Determinants

Patient-Provider relationships. The quality of the patient-provider relationship is important because it has been linked to adherence and treatment outcomes. Beach et al. (2006) found that patients who felt their health care provider knew them as a person were more likely to receive HAART and have an undetectable viral load. These authors described a patient's perception of being known as a person by their provider as the core feature of patient-centeredness (Beach et al., 2006). Other research has identified provider characteristics which have been linked to higher adherence rates among patients as "knowledge of the provider, the way the provider interacts personally with the patient, the practice styles of the provider that denote characteristics as caring, follow-through, and taking time with the clients" (Russel et al., 2004, p. 42). These factors are very similar to the findings in this study of the qualities participants identified as being valued in their health care providers. Conversely, participants also identified negative qualities of providers which centered on disrespectful treatment, lack of HIV expertise and experience, and inattentiveness.

Since participants in this study identified at least one good relationship with a health care provider, it is difficult to ascertain if a poor quality provider relationship impacted participant adherence in any way. However, participant comments do show how engagement in HIV care is directly affected by the patient-provider relationship. Two participants stated refusing to see a particular health care provider, while another stated feeling ignored by physicians and only seeing a physician rarely and only when feeling very ill. These findings are similar to research by Flickinger et al. (2013) who identified that the quality of communication and relationships between patients and providers impacted appointment attendance rates.

It also appears as though the complexity of participants' health care needs can also add strain to the patient-provider relationship. One participant described feeling that physicians mistrust patients with histories of drug and alcohol use when prescribing certain medications for pain management. Also, a high number of participants commented on having co-morbid conditions which caused significant pain. It seems likely that the need for pain management coupled with a history of drug or alcohol use creates strain in the patient-provider relationship, thereby potentially affecting adherence and engagement in care. Matthias et al. (2010) wrote on the difficulties primary care providers face when working with patients with chronic pain care, and state "the uncertainty surrounding opioid-prescribing and concerns of abuse amplify the potential for communication problems between providers and patients with chronic pain" (p.1689).

Mental health status also appears to impact the patient-provider relationships. A study by Jonassaint et al. (2013) investigated the effect of depressive symptoms on the patient-provider relationships through analysis of patient-provider encounters as well as surveys of patients and providers after the clinical encounter. Interestingly, the analysis of audio-recorded encounters, which used a coding system designed to measure patient-provider communication behaviours, did not identify a decreased quality of care by providers of depressed patients living with HIV, but surveys found depressed patients felt less respected by their providers, and providers had lower positive regard for depressed patients (Jonassaint et al., 2013). The authors suggest that providers felt lower positive-regard for their depressed patients living with HIV because they may have viewed these patients as "difficult" and these patients had greater needs which took up more of the providers time (Jonassaint et al., 2013).

While many studies have linked the quality of the patient-provider relationship to increased adherence to HAART (Beach et al., 2006; Lewis et al., 2006; Russel et al., 2004; Malcolm et al., 2003), few have discussed the influence of multiple providers. Participants in this study commented on having a number of health care providers involved in their HIV care and, as would be expected, participants indicated that relationships differed for each provider. This creates more complexity to understanding how the patient-provider relationship impacts adherence to HAART and engagement with HIV-related care.

There also appear to be a variety of contextual factors which impact both patient access to health care providers as well as their relationships with them. Participants commented on being frustrated with having difficulty making appointments when needed, feeling rushed in appointments and seeing multiple health care providers. Participants often attributed these circumstances to the lack of available physicians, and the large number of patients needing to be seen. These factors are affected more by the health care system factors than by the personal characteristics of individual health care providers. Wilson and Rosenberg (2004) reported on data from a national health survey that indicated a low number of Canadians experienced problems accessing health care, but barriers to access were linked to low income and education levels, having a chronic condition or an activity restriction, with waiting times being the most reported barrier to receiving care. The over-representation of those with a low income living with HIV and the fact that HIV is a chronic condition indicates that people living with HIV are much more likely to experience difficulties in accessing health care, or that those with low income may delay accessing care for a variety of reasons. Browne et al. (2011) identified some factors which undermined access to health care for Aboriginal patients in an emergency department. Aboriginal participants' of the Browne et al. (2011) study described feeling judged

by health care providers, and not treated with respect. These findings align closely with the results of my own research.

Side effects and co-morbidities: complicating care and decreasing quality of life.

Participants' experiences of side effects and co-morbidities varied, but the majority expressed experiencing a side effect and/or a co-morbidity which was of concern. The experience of side effects from HAART has been found to negatively impact both mental and physical dimensions of peoples' quality of life (Préau et al., 2007). Also, the experience of side effects has been associated with current and future non-adherence (Trotta et al., 2002). Interestingly no participant cited missing a dose of ARV medications due to side effects, but several felt their side effects and/or co-morbidities were significant causes of stress and discomfort. Future research could look at how the experience of side effects and co-morbidities might affect engagement in care, as people affected by side effects and/or co-morbidities will require greater interaction with the health care system which could potentially add to their burden of being engaged with regular medical care.

Stigma within a health care setting. All participants noted having felt some form of stigma within a health care setting, typically a hospital. Service providers interviewed also commented on their experiences seeing clients facing stigmatizing behaviours within health care settings. Participants' most often associated the stigma and discrimination they faced in a health care setting with provider perceptions of their own drug or alcohol use rather than their HIV status, but participants' also commented on experiences of HIV-related stigma which primarily took the form of provider unease or discomfort when the participant's HIV status was disclosed.

These experiences of stigma are not surprising considering that both being HIV positive and having, or having had, a drug addiction are highly stigmatized in Canada (Room, 2005).

Research has shown that HIV-related stigma in health care settings is a barrier to the delivery and utilization of HIV care and treatment services (Nyblade et al., 2009). Nyblade et al. (2009) point to three causes of HIV-related stigma within health care systems; these are a lack of provider awareness of stigma, fear of contact with patients based on a misunderstanding of transmission, and values which associate HIV infection with immoral behaviour. The experiences of HIV-related or other forms of stigma, in a health care setting can be particularly damaging. Research from the Netherlands looking at the impact of HIV-related stigma in different settings found that participants experienced the most psychological distress when experiencing HIV-related stigma in family and in health care settings (Stutterheim et al., 2009). Stutterheim et al. (2009) stated that the manifestation of HIV-related stigma in a health care setting which was most distressing was awkward social interaction by providers, which corresponds to the most commented on form of HIV-related stigma described by participants in my own study. These authors postulated that stigma in a health care setting was particularly distressing because patients expected providers to be knowledgeable about HIV and at ease with patients living with HIV, but when providers were not at ease patients felt disappointment (Stutterheim et al., 2009).

Some participants commented on avoiding going to the hospital unless absolutely necessary because of their past experiences of stigma from hospital staff. A qualitative study done in Toronto which looked in to homeless peoples' perceptions of "welcomeness" in health care settings similarly found that unwelcoming experiences were distressing and "negatively influenced their desire to seek health care in the future" (Wen et al., 2007, p. 1011). However,

the impact of experiences of stigma, whatever the basis, in health care settings, on participants' adherence and engagement in HIV-related care is more complex because the negative interaction with health care providers in some settings is balanced against the positive interactions with other providers, who usually are more involved in a patient's primary care. It is plausible that participants who experience more stigma within a health care setting like a hospital than in a clinic may avoid hospital based care more than clinic-based care. As suggested in the section on the patient-provider relationship, more research which looks at how the various relationships and encounters with health care providers a person living with HIV has would be useful in understanding how these various interactions affect overall engagement in care and adherence to HAART.

Accessibility of antiretroviral medications. The majority of participants interviewed reported being reasonably satisfied with the method of medication pick-up. However, some issues related to medication pick-up were identified as being either a barrier to access, or as a cause of stress. Mobility problems were factors for one participant who had his HAART given daily with his methadone, another participant commented on the stress involved with being on methadone, and another participant described her anxieties about forgetting to order her medications. Clearly these participants had varying needs in terms of how their medications were accessed, and adapting the method of medication pick-up, or delivery, to meet patient needs is one way to support adherence by addressing some of the common reasons people miss doses. Adherence support programs have been shown to be successful in increasing adherence to HAART among those who had challenges with adherence.

Research done in Vancouver, BC found that ARV treatment programs which employ directly observed treatment (DOT) for ARVs among people who use injection drugs showed promising results in increasing adherence and ultimately reducing viral load for the majority of patients (Tyndall, et al., 2007). The programs utilizing DOT also offered a variety of supports which were adapted to patient need, but included “adherence counselling, assistance provided for housing, addiction treatment, and other social supports (Tyndall, et al., 2007, p. 282).” The DOT component of these programs likely had a positive effect on adherence, but the various other supports which were provided likely played a critical role in improving treatment outcomes by addressing some of the causes of suboptimal adherence.

An evaluation of a similar program in Boston also reported patients had increased adherence, reduced viral load, and increased CD4 cell counts (Behforouz et al., 2004). This program, titled *Prevention and Access to Care and Treatment (PACT)*, utilized DOT, but workers delivered ARVs to patients’ homes, rather than having patients pick up medications at a clinic (Behforouz et al., 2004). Patients in this program also were provided supports which included “management of social crises such as domestic violence and substance abuse, accompaniment to medical and mental health appointments, education about medications and side effect management, and adherence counseling (Behforouz et al., 2004, p. 644). These findings support an argument that social and structural factors play an integral role in adherence to HAART.

Those who experience the most challenges to adherence often struggle with addictions, but also experience the many challenges which accompany living in poverty. Adherence support programs address the suboptimal adherence through delivery of medication or DOT, which supports adherence directly, but also provide added supports which address some of the greatest

challenge to adherence, such as unstable housing. These programs also appear to support engagement in care. A medication adherence support program began serving clients in Prince George after research interviews for this study were completed. As mentioned previously, I was employed as a part-time Outreach Support Worker with this program from November, 2012 to August, 2013. This time frame was after research interviews were completed, but during the analysis and writing phase of my research project.

While 3 participants of this study had directly observed treatment with ARVs because of their enrollment in a MMT program, they also commented on having received supports on education about medications, housing, and other outreach services from nurses, pharmacists and CBAO staff in their communities. The participants receiving daily witnessed MMT all stated that it supported their adherence, but also expressed challenges related to needing to get to the pharmacy. Milligan (2011) also addressed some drawbacks to daily witnessed MMT in Prince George where participants commented that it was stressful, and the inner city location of the pharmacy where MMT was received increased one's risk of using illicit drugs.

Adapting the methods of medication delivery or pick-up to a patient's needs is the key to reducing the barriers to accessing medications. The evidence from adherence support programs is promising in that for some, these programs can support adherence and improve engagement in care as well as address some of the underlying challenges. Evidence suggests that the MMT supports adherence, but challenges also exist. Whether or not MMT works for those who could benefit from it would depend on a variety of factors which include transportation and mobility factors, pharmacy location and hours of operation, and patient satisfaction with MMT to name a few.

The comments from one participant indicated that there may be issues with how people on HAART in BC re-order their medications. No research was found which evaluates patient satisfaction with the process of the drug treatment program (DTP) in BC. An evaluation on the stress caused by the current system, and the possibilities of missed doses from late re-ordering would be useful to determine if the process in place is suitable for all patients enrolled in the DTP.

Involvement with a CBAO. Three key components of participants' involvement with a CBAO were identified as supporting adherence and engagement in HIV-related care; the sense of community and social and emotional support provided from other members as well as staff, opportunities for education about HIV and HIV treatment, and material or tangible supports such as food or rides to a medical appointment.

Community. The importance of social supports, as was discussed earlier, helps people living with HIV in a variety of ways. Having more social supports likely aids adherence to HAART and engagement with HIV-related health care by increasing a positive state of mind, and mitigating feelings of depression, stress and anxiety (Gonzales et al., 2004). Participants' comments regarding the benefits they receive from being involved with a local CBAO show that the social and emotional support provided by staff and other members is greatly beneficial. This finding is congruent with research done in Ontario, Canada, which found users of a CBAO felt a reduced sense of isolation and improved health related quality of life (Crook, et al., 2005). The benefit of these social and emotional supports may be even more important for individuals who have few social supports, and who may feel particularly isolated because of their HIV status. These benefits may also be greater for those involved with a CBAO in a rural setting as the

stigma attached to being HIV positive can be high, and where fewer health and social services are available (Roeder, 2002).

The ability to help others living with HIV was also a benefit of being involved with a CBAO which was discussed by several participants. Ways that participants supported others with HIV ranged from informal discussions with other members of the CBAO, or friends living with HIV, to formalized involvement with HIV education and prevention efforts within the CBAO and beyond. A qualitative study of people living with HIV who provided peer support found a variety of benefits from this involvement including “social acceptance, reciprocal support and personal growth and empowerment” (Marino, Simoni and Silverstein, 2007, p. 67).

Education. Several participants described their involvement with a CBAO as increasing their access to knowledge relating to HIV and HIV treatments. Sources of information were CBAO staff, other CBAO members, and resources available through the CBAO, such as magazines. These findings are congruent with other research identifying CBAOs as important sources of information for people living with HIV (Mutchler et al., 2011; Zukosky, Thorburn and Stroud, 2011). A qualitative study by Mutchler et al. (2011) in Los Angeles found that participants working with a Treatment Advocate employed by a CBAO influenced clients’ “engagement in HIV medical care and decisions to initiate ART” (p.81) through providing education and information. However, these articles do not address the impact of peer-based information sharing which participants in my own research described as being important in terms of receiving useful information and the importance that information came from someone who is also living with HIV. Further research would be useful in determining the effect of peer based networks of information sharing on adherence and engagement in care, as well looking at the consistency and reliability of information shared within these networks.

Material supports. The provision of tangible supports such as food hampers, a ride to a medical appointment, or advocacy in health care and social services fills in the gaps of social and health care service provision, and supports individuals who have needs which are not met by the current level of services available. The provision of these services through a CBAO can support adherence and engagement in HIV-related care through direct means, such as discussions and education about medications, or a ride to a medical appointment, or through indirect means such as a food hamper or housing support. A CBAO supporting an individual in meeting his or her basic needs allows that person to give higher priority to his or her health through adhering to medications and getting to medical appointments.

These findings are supported by a various research findings which link the receipt of ancillary services to entry and engagement in medical care (Conviser & Pounds, 2002; Ashman, Conviser & Pounds, 2002; Messeri et al., 2002). Ancillary services include case management, including medical and social service referrals, mental health and substance use treatment or counselling, housing assistance, transportation, food bank use, advocacy, and emergency financial assistance. While the CBAO is not the only provider of such ancillary services, participant comments suggest that the CBAO staff are the primary providers of these services, and support members in accessing other ancillary services unavailable from the CBAO.

While the benefits of the services provided, and sense of community and social and emotional support provided by the CBAO, comments from participants also indicate certain constraints. The supports provided by the CBAO address many of the needs which exist at the proximal and intermediate levels of the social determinants of health and assist in mitigating some of the underlying barriers to adherence and engagement in HIV-related care. However, these supports only go so far as the existing health and social services and infrastructure can

accommodate. For example, a CBAO staff member can provide housing assistance to a client, but any level of assistance may be fruitless when the appropriate housing infrastructure does not exist. Similarly, CBAOs who increasingly have clients with greater needs are faced with significant funding constraints which negatively impact the services which they can provide (Cain & Todd, 2008).

The work of CBAOs can do much to increase the well-being of their clients and can support adherence and engagement in HIV-related care in direct and indirect ways. The social support which people living with HIV can gain from becoming involved with a CBAO is particularly beneficial for those who feel socially isolated due to their HIV status. This finding seems particularly relevant in smaller communities where the stigma associated HIV is high. Education on HIV and HIV treatment through a CBAO can complement the education provided through primary health care services, whose services are also increasingly constrained. Other supports provided by CBAO, such as rides and accompaniment to medical appointments, food hampers or housing assistance allow people living with HIV to give more energy and time to focusing on their health, rather than searching for a place to stay, or their next meal.

Geographical analysis

Several key differences in the experience of barriers or supports to adherence and engagement in care were identified between both research sites and were described in the results. Participants in Smithers, a rural community, commented more on their experiences of HIV-related stigma and confidentiality issues, having fewer available health care and social service resources, and the need to travel for accessing specialist health care services. These issues were also commented on by participants in Prince George, but to a lesser degree. These findings fit with research on access to HIV care and adherence to HAART in rural areas of the Midwestern

United States where rural participants indicated having significant problems with “the need to travel long distances to medical facilities and personnel; a shortage of adequately trained medical and mental health professionals; a lack of personal or public transportation; and community residents’ stigma toward people living with HIV” (Heckman et al., 1998, p. 365). Similarly, research by Roeder (2002) reported that rural people living with HIV identified scarce financial resources, stigma, and a lack of support groups as barriers to receiving health and social services. Further research in a variety of rural communities in northern BC is needed to get a better understanding of the barriers to adherence and engagement in HIV-related care experienced by people living with HIV in these communities.

Aboriginal ancestry

Research has shown that treatment outcomes with HAART, such as achieving initial viral suppression, and sustained viral suppression are lower for Aboriginal people living with HIV than for non-Aboriginal people living with HIV, but results were similar for both Aboriginal and non-Aboriginal people living with HIV who used injection drugs (Martin et al., 2010). A study done in two community health centres in Vancouver and Prince George BC, which measured the effect of a chronic care model on HIV clinical outcomes found “Aboriginal ancestry was not associated with better or worse outcomes at baseline or at follow-up” (p. 650), but found that stable housing was the greatest predictor of survival (Tu et al., 2013). The authors interpreted this finding as being due to Aboriginal and non-Aboriginal patients of these clinics experiencing poverty, drug addiction and social marginalization at similar levels (Tu et al., 2013). A meta-analysis of HIV incidence and prevalence in Canada found that Aboriginal and non-Aboriginal people had similar incidence and prevalence rates among most risk groups, but that Aboriginal people using injection drugs, street youth and female sex workers had higher incidence and

prevalence than non-Aboriginal people in these same risk groups (Duncan et al., 2010). These findings indicate that over-representation in HIV prevalence and poorer HIV treatment outcomes among Aboriginal peoples is largely due to factors associated with the social determinants of health where Aboriginal peoples are disproportionately living in circumstances where there is an increased HIV exposure risk, and greater barriers to HIV treatment.

Research has also identified that an affiliation with an Aboriginal identity can be health promoting, and buffer some of the negative effects of poverty and discrimination (Jackson & Reimer, 2005). Similarly, Walters and Simoni (2002) propose the effect of life stressors, such as historical trauma, on health can be "...moderated by cultural factors such as identity attitudes that function as buffers, strengthening psychological and emotional health and mitigating the effects of stressors" (p. 521). These findings are congruent with participant comments regarding their feelings of community, pride and spirituality which they associated with their Aboriginal ancestry.

Increasing the cultural competency of health care providers has been recommended to increase the quality of HIV care received by Aboriginal patients and to reduce barriers to care (Barlow et al., 2008; Jackson & Reimer, 2005). Two participants spoke of issues with health care providers which related to a lack of cultural competence, but most felt that their Aboriginal ancestry did not affect the quality of the HIV-related health care they received. This finding may be due to a variety of reasons. For one, more participants spoke to feeling discriminated against by health care providers based on their actual or perceived use of drugs, and only one participant commented on feeling discrimination from health care providers based on her Aboriginal ancestry. Second, in one research site, most participants attended the same primary care clinic, and staff at this clinic were trained in providing culturally competent care. Increasing the cultural

competency of health care providers will make health care settings more welcoming environments for Aboriginal people, and therefore can increase engagement in HIV-related care of Aboriginal people living with HIV.

Distal social determinants of health and structural violence

It is the proximal social determinants of health which most directly influence a persons' lived experience. The intermediate social determinants of health, such as health care system factors, or availability of support services from a CBAO, influence the quality of health care and social service support people living with HIV can receive. The distal social determinants of health are those factors which "have the most profound influence on the health of populations because they represent political, economic, and social contexts that construct both the intermediate, and proximal determinants" (Reading & Wien, 2009, p. 20). Linking the intersecting experiences of participants described as proximal and intermediate determinants to the distal determinants is an important task in understanding the ultimate causes and possible solutions to health inequities. In this section the distal determinants which appear to have the greatest influence on participants' adherence to HAART and engagement in care will be discussed.

Social attitudes, policy and funding.

The experiences of stigma and discrimination described by participants point to the prevalence of prejudicial attitudes within Canadian society. While these attitudes may differ in different communities all participants felt the impact of stigma and discrimination whether it was based on HIV status, perceptions of drug use, or racism. The presence of these attitudes is a form of structural violence as they cause harm to the people affected by them. A CBAO staff member spoke of "pockets of safety" within the community which were described as sources of

refuge for people living with HIV. This term illustrates the point that the effects of stigma and discrimination can make one's community feel like an unsafe and unwelcoming place to live. Attitudes of discrimination towards people living with HIV also have a component of blaming those for their illness, and the circumstances in which they live. This attitude is identified as a common one in North America where "...success and failure is attributed to the individual, with little notice of the larger social and political realities that inform an individual's circumstances and choices" (Blacksher 2002, p. 455). These attitudes not only impact people living with HIV with their interactions within their community, but can influence policy and funding decisions as well.

Several participants, including CBAO staff, identified serious constraints with health care and social service provision. Several authors have identified the proliferation of a neoliberal ideology within governments in Canada which has led to cutting funding for needed services which most often harms the most vulnerable citizens (Chouinard & Crooks, 2005; Morrow, Hankivsky & Varcoe, 2004). These funding priorities relate back to social attitudes about who is deserving of added support and who is not. Substance users and people living with HIV are two of the most discriminated against populations in Canada (Room, 2005) and therefore the underfunding of the services for these populations is not surprising.

However, it must also be acknowledged that in BC HAART medications are provided free of charge, and there has recently been increased funding to increase testing for HIV and uptake of HAART. These measures not only benefit individuals, but also aim to reduce transmission of HIV. However, real progress in supporting individuals with adherence and engagement in HIV-related care will require action on the social determinants of health, such as

funding for more housing options, along with targeted interventions to increase HIV testing and treatment.

Colonialism.

While not all participants interviewed in this study identified as being Aboriginal, the majority did. The role of Aboriginal ancestry in influencing participant experience of HAART was discussed previously and this section will look to the broader impact of colonialism as a distal determinant of health. The over-representation of Aboriginal people in HIV prevalence rates, and the worse HIV treatment outcomes of Aboriginal people living with HIV as compared to non-Aboriginal people living with HIV speak to the continued impact of past and present colonial practices which cause harm to Aboriginal peoples in Canada (Barlow et al., 2008). Duncan et al. (2011) name colonialism, discrimination and poverty as the prominent social forces of structural violence affecting Aboriginal peoples in Canada which increase risks for HIV infection. These same factors which create risk for infection also create barriers to appropriate HIV treatment. Past colonial practices such as dislocation from traditional lands, and assimilative policies, such as the residential school system, are key to explaining the inequities in health observed today between Aboriginal and non-Aboriginal peoples in Canada (Reading & Wien, 2009). An example of one way a colonial practice impacted a participant's level of engagement in care was given when a participant directly linked her experience with the residential school system with a lack of trust in some health care providers. It must also be acknowledged that the current relationship between Aboriginal peoples and the Canadian state is not a just one, and colonialism remains when Aboriginal self-determination is denied (Asch, 2001). For indigenous peoples the right to self-determination has been described as the most important determinant of health because it impacts all other determinants of health (Reading &

Wien, 2009). Colonialism and the presence or lack of indigenous self-determination then appear to be critical in understanding the context in which an Aboriginal person living with HIV will experience barriers and supports to adherence and engagement in care.

Linking participants' experiences of adherence to HAART and engagement in HIV-related care to the distal social determinants of health, and the influences of structural violence allows one to better understand some of the root causes of barriers, and the potential paths to increasing supports to adherence and engagement in care. These distal social determinants and examples of structural violence mentioned here are only a few, and a complete discussion of these factors requires a greater analysis than can be provided here. However, linking participant experiences to broader social forces is an important step to better understanding the context in which those experiences occur, and how individuals are embedded in a larger social structure.

Barriers and supports: mechanisms of action

The goal of this research was to identify barriers and supports to adherence to HAART and engagement with HIV-related care in two communities in northern BC with the aim of providing insight in to how treatment with HAART can be improved in this region. Participants' experiences reveal the complex and intersecting ways in which various factors create barriers or supports to adherence and engagement in HIV-related care. Each factor, such as unstable housing, or a poor patient-provider relationship, can lead to reduced adherence or engagement in care in different, and sometimes multiple ways. There appear to be some common themes to how factors can function as a barrier and it may be useful to provide a discussion on three of these themes; these will be described as mechanisms of action.

The first mechanism to be discussed focuses on one's prioritization of needs. A variety of situations or circumstances may create a hierarchy of needs for a person where his or her health care needs, such as adhering to medications and seeking care, become less of a priority than other needs. These other needs include meeting basic food, shelter or safety needs, establishing or maintaining relationships, or struggles with an addiction to drugs and/or alcohol. For some participants who lived in marginalized circumstances, and struggled with addictions, being HIV positive was not the most pressing concern in their lives. There is a clear link between one's socioeconomic status and where adherence to HAART and engagement in care fall in a person's hierarchy of needs.

The second mechanism functions through the prevalence of chronic stressors and the development of depressive symptoms, and reduced quality of life. The presence of depressive symptoms for people prescribed HAART can influence adherence and engagement in care. Simoni, Frick and Huang (2006) state that "depressive symptomatology is one of the most consistent predictors of non-adherence" (p. 75). Depressive symptoms can be affected by both biological and social factors. The chronic stress associated with living in poverty, experiences of stigma, and feelings of social isolation are social factors which likely increase the risk a person will experience depressive symptoms. While the association between stress and depression is more complex than will be discussed here, there is evidence of the causal relationship between experiences of stress and the development depression (Hammen, 2005). Depressive symptoms can impact one's ability or desire to adhere to medications or be engaged in health care (DiMatteo et al., 2000). Depressive symptoms and life stresses may also lead to the use of drugs and alcohol as a coping mechanism, thereby potentially creating more challenges to adherence and/or engagement in care (Power et al., 2003).

The purpose of linking the often chronic experience of stress to depression is that this link establishes how a person's social environment can lead to reduced adherence, even if the stressors do not appear to create a direct challenge to adherence or engagement in care. Pearlin (1989) situates stress in social contexts and links stress experience to socioeconomic status.

Many stressful experiences, it should be recognized, don't spring out of a vacuum but typically can be traced back to surrounding social structures and people's locations within them. The most encompassing of these structures are the various systems of stratification that cut across societies, such as those based on social and economic class, race and ethnicity, gender, and age. To the extent that these systems embody the unequal distribution of resource, opportunities, and self-regard, a low status within them may itself be a source of stressful life conditions (Pearlin, 1989, p. 242).

The fact that many people living with HIV also live in marginalizing circumstances points to the potential impact of the influence of a stress and depression pathway of reduced adherence and engagement in care.

One particular form of stress which appears to be significant, especially for those living in poverty, is a loss of autonomy. Participant comments indicating the stress caused by their loss of autonomy included stresses associated with methadone treatment, living in a shelter or supported housing, lack of food choices, obligations to get to a variety of appointments including health care, mental health, social work or probations, and financial constraints. The sense of a loss of control, and the actual reality of having less control of important aspects of one's life can have detrimental consequences. Autonomy, or one's sense of control within their life, is discussed by Wilkinson (2005) as having an important effect on peoples' health. Wilkinson

(2005) states a “sense of control is more a social concept than is often realized, and is often affected by how much you are subordinated by the authority and instructions of superiors” (p. 75). Wilkinson’s (2005) discussion on autonomy primarily consists of reference to research which finds higher morbidity and mortality among lower level employees who, it is hypothesized, experience chronic stress from their lack of control and subordination within their work place, and thereby suffer from the physiological responses to this chronic stress. A similar mechanism may be at play for those living in poverty. Reliance on shelters, or supported housing, and on agencies to provide meals or food hampers, or financial assistance removes a level of control in one’s daily life. While these services are critically important to providing the basic necessities of life and well-being, the loss of autonomy appears to be a factor in the peoples experience of stress and may then impact ones adherence and/or engagement with HIV-related health care.

The final mechanism addresses one’s ability to access medications and care. Access is affected by a variety of factors including ease of mobility or travel, fear of negative encounters in places where medications or care are received, or fear of being outed when accessing medication or care. Several participants mentioned access difficulties, and these are also represented in the literature on HAART adherence.

Prioritization, stress and depression, and access issues are three of the primary methods in which a factor can function as a barrier to adherence and/or engagement in HIV-related care. Some factors may function through more than one mechanism, such as a negative encounter with a health care provider can be a stressful experience, potentially influencing depressive symptoms, but could also create a barrier to accessing medical care as the individual may not want to seek medical care because of a fear of another negative encounter. Conversely, factors

which allow one to prioritize adherence and engagement in care, reduce stressors and feelings of depression, and support access to care and medications can all potentially support adherence and engagement in care.

Conclusion

This chapter provided a discussion of the findings of my own research with reference to the relevant academic literature. The broad nature of the factors related to adherence to HAART and engagement with HIV-related care speak to the complexity of these phenomena. People are embedded in their social worlds, and therefore social forces have a tremendous effect on one's lived experience. The literature supports this view, but all too often focuses the research gaze narrowly on individual factors without linking these to broader social forces. By looking at the proximal, intermediate and distal social determinants of health my research is able to link individual experience to the relevant social forces which have an impact on those experiences.

Many of my findings aligned with the literature on factors which can challenge or support adherence to HAART and/or engagement in HIV-related care. The importance of social supports, relationships with providers, access to a CBAO, the impacts of stigma, unstable housing and food insecurity are some of the factors which participants' of my study identified as being important which were similarly discussed in the literature. My research also differed from much of the academic literature on certain topics. Most of the literature published on issues of housing as related to adherence to HAART and engagement in HIV-related care took a quantitative approach housing status is described simply as stable or unstable. The qualitative approach I used provided further insight in to housing qualities which were relevant to adherence. These qualities included proximity to services, privacy, and safety.

My research also identified several factors which were relevant to participants' adherence and engagement in care, but which were not found elsewhere in the literature. Participants' difficulties accessing supplemental funding for health care needs has not been mentioned in research on adherence in BC to my knowledge. The stresses of HIV disclosure and/or non-disclosure and the potential influence this stress has on adherence and engagement in care is to my knowledge a novel finding. Finally, the way that socioeconomic status can affect one's control of their environment and thereby potentially mediate the risk of exposure to stigmatizing experiences was not found in the literature.

By linking participants' descriptions of their lived experience to broader social forces my research was able to identify some of the underlying root causes of the barriers and supports to adherence and engagement in HIV-related care. This approach, and the qualitative methods used, allowed the identification of some novel findings, as well as a more nuanced analysis of some common factors associated with adherence and engagement in care.

Chapter 6: Conclusions

Summary of key findings

The purpose of this study was to investigate the experiences of people prescribed HAART in northern BC with the goal of identifying and understanding the various barriers and supports to adherence to HAART and engagement in HIV-related care in order to inform ways to improve HIV care and treatment outcomes in this region. This was investigated by undertaking a qualitative study using an interpretive phenomenological approach with in-depth interviews. Key findings show that there is diversity in the experience of living with HIV in northern BC. All participants interviewed had unique perspectives, backgrounds and experiences. In total 11 participants were interviewed with 10 participants taking part in a follow-up interview. An interpretive phenomenological methodology guided the research design and data analysis of this research.

For HAART to work optimally a high adherence rate and continual engagement in health care are needed. Participants' ability to meet these demands ranged from one end of the spectrum to the other. Through the investigation and analysis of these unique and individual lived experiences of treatment with HAART in northern BC some common themes emerged. The importance of social supports, having stability and security in one's home, feeling trust in health care providers, and an ability to access needed medications and health care are but a few of the common themes which participants linked to supporting adherence and engagement in care. These findings highlight how individual experiences are influenced by the social context in which people live, and therefore how the social context can affect adherence and engagement in care. The significance of these findings is that efforts to improve adherence to HAART and

engagement in HIV-related care must not only be individually focused, but must take in to consideration the ways various social determinants of health intersect in an individual's life.

Research influencing practice

Having completed my research interviews prior to beginning my work as an Outreach Support Worker with the medication adherence support program (MASP) I was aware of some of the key characteristics that participants found helpful in service providers. I was keenly aware of the importance of building relationships and trust with clients, and the various challenges that many clients faced in their daily lives.

Also, as an Outreach Support Worker with MASP I had a greater opportunity to build relationships with individuals living with HIV, and the health care and service providers who support them. I gained greater insight in to the workings of the health care system, financial assistance mechanisms, mental health and addiction treatment, housing issues and supports, and food hamper programs. I continually reflected on how the findings from my research interviews compared with the experiences of MASP clients. Ultimately this experience as an Outreach Support Worker gave me a deeper understanding of the phenomenon of treatment with HAART in Prince George. I believe this experience allowed a more nuanced analysis of my research interviews and guided my selection of key themes described by participants. In many ways my initial interpretations of interviews were reinforced by my experiences working in MASP. An example of this is the importance of housing to adherence and engagement in care. The quality of housing was discussed by several participants as being very important to their well-being, and this theme was reinforced again and again in my work. By supporting clients in finding housing I also witnessed the challenge faced by many in finding safe, comfortable and affordable housing, and the stress and hardship of homelessness. Of the many ways that HIV treatment

could be improved in northern BC it is creating more housing options which meet peoples' varying needs that could result in the most drastic improvements in treatment outcomes.

Suggestions for future research

This research identifies some of the key barriers and supports to adherence to HAART and engagement in HIV-related care in Smithers and Prince George BC. These communities are not necessarily representative of the majority of northern BC communities in important ways. Prince George is the largest city in northern BC, and therefore there exists greater access to health care and social services. Smithers is a smaller community, but is one which has both a CBAO and does not experience health care provider shortages as readily as many other communities in northern BC. Therefore the experience of living with HIV and getting treatment with HAART is likely very different in communities without a CBAO and with less access to health care providers. Research in a variety of communities throughout northern BC would be useful in identifying the varying needs and circumstances within those communities.

Another area for further research is looking at the impact of alcohol use on adherence and engagement in care. The negative impact of alcohol use was mentioned by participants in Smithers to a greater degree than by participants in Prince George, but there was evidence that alcohol use contributed to reduced adherence in Prince George as well. In BC it is primarily injection drug use that is investigated in relation to adherence, but further investigation in to alcohol use and its effect on adherence and engagement in care, may inform better harm reduction strategies, identify addiction treatment needs, and inform specific strategies for increasing adherence and engagement in care.

Further research on how HIV disclosure can affect adherence and engagement in care may support ways to better inform those living with HIV on the possible implications of disclosure; both good and bad. More research which investigates how socioeconomic status mediates a variety of factors associated with adherence and engagement in care may provide further insights in to the importance of socioeconomic status on personal health. While much research has been done on the importance of the patient-provider relationship, the reality is that many patients now have multiple providers. More research on the impact of multiple patient-provider relationships would provide insight in to which relationships are most critical, and how multiple providers can work together most effectively.

The issue of HIV and/or addiction related stigma was common throughout all interviews. This problem shows that more needs to be known about how to address these forms of stigma, and how to educate the wider population on how stigma affects people, and to address common misconceptions and prejudices which inform stigmatizing attitudes. Research on this subject would hopefully inform ways to reduce both HIV and addiction related stigmas.

Recommendations for improving HIV care outcomes in northern BC

The findings of this research can inform a variety of ways in which HIV treatment outcomes can be improved in northern BC through supporting adherence and engagement in HIV-related care. As mentioned earlier, addressing the lack of affordable, safe and comfortable housing options would support many in providing greater stability and routine, which in turn would support adherence to HAART. Increased funding for food hamper programs and soup kitchens would allow these organizations to serve more people as well as tailor services which can meet individual needs. Efforts which promote greater understanding of HIV and addiction in the broader population of northern BC are also needed in order to reduce the level of stigma,

which can have profound impacts on the well-being of people living with HIV. Increasing the amount and accessibility of government financial supports would do much to increase access to medical care, make housing more affordable and increase food security.

Those who work in the health care system need to be keenly aware of the potential consequences their actions may have on making those living with HIV feel stigmatized or disrespected. The fact that most participants reported feeling stigmatized because of health care providers' assumptions regarding substance use also shows that providers need more education on substance use, and on working with people who struggle with an addiction.

The success of various adherence support programs, and the successful implementation of MASP in Prince George shows that these programs can support people who struggle with the high level of adherence needed for HAART to be successful. Scaling up adherence support programs in Prince George and in more communities throughout northern BC is likely to improve the HIV treatment outcomes for many in this region. However, these programs would need to be tailored to the individual community needs, and therefore how these programs are organized and the types of services they provide would likely differ between communities.

Many participants commented on benefits of their involvement with a CBAO. Participant comments showed that the CBAO provided services and supports which either directly or indirectly addressed many of the identified barriers to adherence to HAART and engagement with HIV-related care. The sense of community and social supports which many participants found at the CBAO appeared to be critical to a sense of well-being. Unfortunately, these organizations are only present in a few communities in northern BC and the services they provide are circumscribed by funding constraints. Increasing the funding for CBAOs and

increasing their presence in different communities throughout northern BC would do much to improve the many factors which impact adherence and engagement in care.

Finally, action on the distal social determinants of health is required in order to influence the intermediate and proximal social determinants. The continuing impact of colonisation needs to be acknowledged and addressed, and a more just relationship between the Canadian state and First Nations needs to be established. Equity must be a principle guiding policy decisions and funding allocation in order to ensure that fundamental rights are met in terms of basic needs, such as housing and food security, and access to health care.

Conclusion

The majority of participants interviewed can be described as living within marginalizing circumstances. The circumstances are most profoundly shaped by poverty and social exclusion in various forms which create direct and indirect barriers to adherence and engagement in care. Service organizations, such as CBAOs, health care organizations and providers who understand the effects of various forms of social marginalization on their clients can provide services which address and attempt to mitigate the barriers faced by clients. However, improving HIV treatment outcomes in northern BC will require not only greater support for health and social services organizations to increase their ability to provide needed services, but will require action at the multiple levels of the social determinants of health.

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Appendix

Interview Question Guide

Introducing questions provide the structure of the interview and the responses will guide what other questions will be asked in the interview. These questions will attempt to get rich descriptions about the participant's experiences, as well as build a rapport between the interviewer and participant.

1. Please tell me about yourself.
2. Please tell me about your health.
3. Please tell me about your experiences with HIV treatment.
4. Please tell me about your relationships with the people involved in your HIV treatment.
5. How do you think living in Northern BC affects your HIV treatment?
6. What are your thoughts about HIV treatment in general?

The participant will be asked to elaborate on particular responses from the introducing questions. Follow – up questions will attempt to extend the participants responses to the introducing questions. The majority of interview questions could all be considered types of follow – up questions if they are asked based on responses from the introducing questions.

Probing questions ask the participant to elaborate on the content of a particular response to an introducing question (Kvale, 1996). This type of question may include asking the participant for specific examples or a description of an event, such a visit to a health care provider.

The goal of specifying questions will be to elicit more precise descriptions from the participant (Kvale, 1996). An example of a specifying question is: “what was your reaction to that situation?”

Direct questions are not open ended, and care needs to be taken to ensure that they do not become leading questions. An example of a direct question is: “would you consider that situation a barrier to your HIV treatment?”

Indirect questions may ask for the participant's views or attitudes about HAART which are more general, and not specifically related to the participant's own experiences with HAART. An

example of an indirect question is: “what are some important factors that support people with their HIV treatment in Prince George?”

Structuring questions will be used to guide the focus of the interview, and may be employed to change the topic of conversation. An example of a structuring question is: “let’s talk about your experiences with health care providers now.” It is important that these types of questions are used politely and do not cut off a participants responses.

Interpreting questions will be used to validate or clarify responses from the participant. An example of an interpreting question is: “would you say that the event you just described created difficulties for you to access health care?” Interpreting questions differ from direct questions in that they are based on a response that indicated a particular interpretation to the interviewer, but was not explicitly articulated by the participant.