## Table of Contents

Introduction 1
Section 1: Dissemination of Results / Findings
Migration, Mobility and the Health and Well-Being of Aboriginal Two-Spirit/LGBTQ People: Findings from a Winnipeg Project
Janice Ristock, Art Zoccole, Lisa Passante
Section 2: Student Papers 31
An investigation of the Determinants of Adherence to Highly Active Anti-Retroviral Therapy (HAART) in Aboriginal Men in the Downtown Eastside (DTES) of Vancouver
Meck Chongo, Josée G. Lavoie, Ross Hoffman, Mamdouh Shubair 32
Call for Paners

# An Investigation of the Determinants of Adherence to Highly Active Anti-Retroviral Therapy (HAART) in Aboriginal Men in the Downtown Eastside (DTES) of Vancouver

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#### **ABSTRACT**

The eradication of HIV is not yet possible; therefore persons undergoing treatment must take highly active antiretroviral therapy (HAART) regularly. In British Columbia (BC), antiretrovirals are distributed at no cost but the HIV-related annual mortality rate stands at 9% (Vancouver Native Heath Society [VNHS], 2009). The Aboriginal population in BC alone makes up 13% of new HIV infections, many of whom are less likely to engage in effective care (Lima et al., 2006; Tu et al., 2008). The purpose of this study was to investigate the determinants of adherence to HAART in Aboriginal men in the Downtown Eastside (DTES) of Vancouver and to offer culturally sensitive recommendations aimed at improving access to HAART and reducing deaths due to HIV/AIDS. This research was a phenomenological study applying the methods of the Vancouver School of Doing Phenomenology. Recruitment was through purposive and snowball sampling. Data were collected from twenty-two participants using interviews and a focus group.

Five main themes emerged from the analysis: patient factors; inter-personal factors; support structures; history of trauma/ residential school; and medication-related factors. A host of psychological and socioeconomic factors affect adherence. The presence of stigma and discrimination and a negative patient/care-provider relationship reduce adherence. Various support structures improved adherence. A history of trauma contributed to reduced adherence or led to development of survival skills. Finally, a complex treatment regimen and development of medication side effects reduced adherence. Some of the adverse determinants may be overcome by providing better education about HIV/AIDS, stigma and discrimination, Aboriginal history, the need for adherence, professional and lay support, and encouraging patients to follow traditional ways of living.

#### INTRODUCTION

HIV/AIDS has had a tremendous impact on society. It is one of the most devastating infectious diseases since the 1917-1918 influenza epidemic that killed at least 50 million people around the world in approximately six months (Johnson & Mueller, 2002). Aboriginal<sup>1</sup> People Living with HIV and AIDS (APHAs) continue to be overrepresented

<sup>&</sup>lt;sup>1</sup> "Aboriginal" is defined in the Constitution of Canada, Section 35 of the Constitution Act 1982, and refers to all peoples of Indian, Inuit and Métis heritage, regardless of where they live in Canada or whether they are "registered" under the *Indian Act* of Canada.

in the HIV epidemic in Canada. There are roughly one million Aboriginal peoples in Canada, accounting for approximately 3.8 percent of the total population (Statistics Canada, 2008). However, the Public Health Agency of Canada (PHAC) estimates that Aboriginal peoples accounted for an estimated 8.0 percent of persons living with HIV in Canada at the end of 2008 and an estimated 12.5 percent of all new HIV infections in 2008. This shows an overall infection rate that is nearly 3.6 times higher than among non-Aboriginals (PHAC, 2009). In British Columbia (BC) alone, there are approximately 55 to 70 new positive HIV tests among Aboriginal peoples per year. While Aboriginal peoples represent approximately 5 percent of the BC population, they account for 15 to 17 percent of all new positive HIV tests each year (BC Provincial Health Officer [PHO], 2009).

Since the eradication of HIV is not yet possible, persons undergoing treatment for HIV must take their Highly Active Antiretroviral Therapy (HAART) regularly (Ickovics & Meade, 2002). In BC, antiretrovirals have been distributed at no cost to eligible HIV-infected individuals through the BC Centre for Excellence in HIV/AIDS Drug Treatment Program since 1992 (BC-CfE, 2010). Since HAART was first introduced in 1996, antiretroviral therapy has been beneficial in the management of HIV (Carpenter et al., 1996; Cu-Uvin et al., 2000; Hogg et al., 1997), and in reducing AIDS-related death rates, opportunistic infections, and hospitalization (Hogg et al., 1999; Murphy et al., 2001). Despite these advances, the full benefit of HAART remains difficult to achieve due in part to incomplete adherence.

Adherence is a primary predictor of treatment success (Bangsberg, 2006) and taking 95 percent or more of doses is required for full viral suppression (Department of Health and Human Services [DHHS], 2009). However, HAART is a long-term treatment, and therefore maintaining a high level of drug adherence often represents a big challenge for the patient (Paterson, et al., 2000). Not only do APHAs have sub-optimal access to HAART (Vancouver HIV/AIDS Care Coordinating Committee, 2000), they also have shorter survival rates than non-Aboriginal persons (Lima et al., 2006). A high proportion of AIDS mortality is due to poor adherence to therapy among the disadvantaged or marginalized. The rate of deaths due to HIV disease for the Status Indian population has more than doubled since 1993 (0.8 per 10,000 in 1993 to 1.9 per 10,000 in 2006), while the rate for other residents has decreased significantly in the same time period (0.8 per 10,000 in 1993 to 0.2 per 10,000 in 2006). Furthermore, aggregate regional data for 2002–2006 show that the Status Indian rates of death due to AIDS were significantly higher than the rates for other residents in BC, and in almost all health authorities (BC PHO, 2009).

Given that 18% of Canada's estimated total HIV-positive population lives in BC, and that the province represents approximately 13% of the overall population of Canada, BC will continue to have a disproportionate share of the HIV burden. The objectives of this study were to:

- 1) Investigate the determinants of adherence to HAART in Aboriginal men in the DTES of Vancouver and
- 2) Offer culturally-sensitive recommendations to better address the effects of the determinants aimed at improving adherence and reducing deaths due to HIV/AIDS.

The involvement of both sexes should be a pre-requisite to the improvement of HIV/AIDS-related health for them and their partners. The focus of this study was on men because men in Canada have become less vigilant in taking consistent HIV risk reduction measures (Hogg et al., 2001) and knowledge gaps pertaining to sexual-related health still exist (Canadian Council of Learning, 2009). In 2006 in BC, the greatest number of new HIV positive infections was reported among men (CDC, 2010). In addition, the median age at first intercourse has steadily declined (Hansen, Mann, McMahon, Wong, 2004; Maticka-Tyndale, Barrett, & McKay, 2000), with males more likely to have had sexual intercourse at an earlier age than their female counterparts of the same age (Boyce et al., 2003). The proportion of males reporting two or more partners is almost double that of females, with only half of the men reportedly using a condom in their last sexual encounter (Mehrabadi et al., 2008). Furthermore, Aboriginal males are less likely than females to be tested for HIV (Assembly of First Nations [AFN], 2002-2003) and males are less likely than females to access HAART (Tu et al., 2008).

Oftentimes, the male partner is usually substantially older than the female partner. For each year the man is older, the likelihood of consistent condom use decreases (Manlove, Ryan, & Franzetta, 2003). Furthermore, public messages promoting greater male responsibility are lacking (Maticka-Tyndale, McKay, & Barrett. 2001). Given that risky behaviour is still occurring at alarming rates, it is necessary for all men to receive relevant knowledge, motivation, behavioural skills and health services to enable them to meet responsibilities of sexual behaviour, and if living with HIV/AIDS, adhere better to HAART and live longer, healthier lives. Listening to stories about what factors affect the adherence to HAART for the men in this study was therefore a huge first step.

## **Understanding the Effects of Colonialism**

Aboriginal peoples in Canada have faced cultural oppression through policies of forced assimilation on the part of Euro-Canadian institutions and experienced wave after wave of debilitating shocks and traumas that left whole nations of people reeling and broken, since the earliest periods of contact (Barlow, 2009; Lane et al., 2002). Particularly notable was the establishment of the residential school system. "Residential schools

officially operated in Canada between 1892 and 1969" (Aboriginal Healing Foundation [AHF], 2001, p. 7), but government-run and band-run schools continued well into the 1990s (AFN, 2010; Barlow, 2009). The purpose of residential schools was to strip Aboriginal children of their culture, in order to destroy Indigenous forms of governance, community organization, solidarity, and cohesion, and to promote the assimilation of Aboriginal peoples to a society modeled on European cultural traditions (Wade, 1995).

While poor adherence and high mortality rates give an idea of how many lives have been touched by the historic trauma/residential school legacy, they cannot begin to capture the physical, psychological, spiritual and cultural harm inflicted on survivors, their families and communities (Dion-Stout & Kipling, 2003). Intergenerational trauma continues to affect the health and well-being of young Aboriginal peoples (Mehrabadi et al., 2008; Yellow Horse & Brave Heart, 2004). The eventual impact of trauma was to generate a wide range of dysfunctional and hurtful behaviours (such as various addictions, physical and sexual abuse) which then began to be recycled, generation after generation inside communities (Lane et al., 2002). Still, the relationship between historic trauma/residential school legacy and adherence has generally been assumed, rather than investigated. Understanding the mechanism by which health care disparities exist, by determining what other aspects of being Aboriginal increase their risk of mortality after initiating HAART, can provide potential targets for intervention in this vulnerable population. Results could be further extrapolated to the understanding of health care inequalities amongst other marginalized populations (Lima et al., 2006).

#### **METHODOLOGY**

This study was conducted in Vancouver, a city with an estimated Aboriginal population of 11,145 (Statistics Canada, 2008). The study involved Aboriginal men from the Downtown East Side, (the poorest neighbourhood in Canada), particularly those who attended and/or were serviced by the Vancouver Native Health Society (VNHS) clinic, were more than 25 years of age, and were currently on HAART. For seven months prior to beginning this study I was a volunteer at the VNHS clinic. During this period, through my attendance at events relevant to historical trauma and/or HIV/AIDS at the VNHS clinic, and several informal discussions with APHAs, it was noted that adherence to HAART was a problem, hence the birth of this study. This interaction and my continued presence at events ensured that participants were able to decide whether to take part in the study from an already established relationship of trust. The VNHS clinic was selected as the main recruitment site because the clinic's number of HIV positive patients on HAART had risen from 294 (53 percent Aboriginal) in 2007-2008 to 349 (57.6 percent Aboriginal) in 2008-2009, and stood at 403 at the beginning of 2010 (VNHS, 2010).

Phenomenology was chosen as the method of inquiry for this study because it is based on the premise that events and objects can only be understood from a subjective perspective (Speziale & Carpenter, 2007). Phenomenology was suited to this study precisely because only APHAs who have been on HAART can tell the story of their lived experiences: they are the experts in telling their story. This lived experience is true or real in one's life and, as such, gives meaning to how a phenomenon is perceived by that individual (Giorgi, 1997). The approach of the Vancouver School of Doing Phenomenology (Anderson, 1991; Halldorsdottir, 2000, p. 57) was utilized. The method encourages respect for each participant in the study who is seen as a truth-telling co-researcher or dialogue partner (Halldorsdottir, 2000; Ricoeur, 1990). The method recognizes that, in order to be as open as possible, to be ready to hear something new and to truly take in what the dialogue partner is saying, it is important to bracket (Ashworth, 1996; Lopez & Willis, 2004) preconceived ideas about the phenomenon being studied. The Vancouver School also recognises that it is impossible to be totally free of preconceived ideas. It is possible, however, to bring them into view by using a reflexive journal (Lincoln & Guba, 1985).

Care was taken to ensure the interviews were conducted in a manner that did not harm participants either physically or psychologically, and that respected people's time, space and understanding of the community structure; as well as cultural, political and social protocols. I met with VNHS clinic personnel and APHAs to discuss logistics pertaining to the study. Ethics approval and a letter of permission to conduct this study were then obtained from the Research Ethics Board at the University of Northern BC and the VNHS Research Advisory Committee respectively. The CIHR Guidelines for Health Research Involving Aboriginal People (2007) were followed and the project was guided by the principles of community ownership, control, access and possession (OCAP). Advice from Aboriginal community members, one elder, and APHAs from across Vancouver was sought. Research questions were identified by members of the APHA community and community investigators at the VNHS who were involved in every stage of the research process. The data were presented to participants first, and then to the VNHS for validation, and to be used for their advocacy activities. This work resulted in two funding proposals to expand services at VNHS.

Recruitment was mainly conducted through collaboration with the VNHS, and the non-random methods of purposive sampling and snowballing (MacNealy, 1999). For maximum variability, people who represented the widest variety of perspectives possible within the range specified by their purpose (Higginbottom, 2004; Marlow, 2005) were included. A demographic summary is provided (see Table 1).

Table 1: Participant demographic summary

Age (years)	Range 39 – 56	Mean 47	Mode 43
Time HIV diagnosis	Time HIV diagnosis Range 1987 - 2008		Mode 35 years
3.5	Single/Separated	Married/Co-habiting	Widowed
Marital status	68%	27%	5%
Housing	BC housing	Temp hotel room	Own house/Other
Housing	64%	27%	9%
T 1 (G) (	Disability allowance	Seasonal/PT job	Unemployed
<b>Employment Status</b>	50%	32%	18%
Education Level	Some high school	High school	Elementary school
Education Level	68%	27%	5%

First, 10 one-to-one in-depth interviews were conducted by using open-ended questions that allowed participants to contribute as much detailed information as they desired, fully expressing their viewpoints and experiences (Turner, 2010). Second, one focus group discussion (Krueger & Casey, 2000; Mack et al., 2005) was conducted, with another 14 participants. The focus group and interviews were transcribed and entered into the NVivo qualitative data software program for coding. Data review and analysis were done in conjunction with data collection. The analysis was done using the qualitative technique of thematic analysis, which incorporates the inductive, bottom-up approach (Braun & Clarke, 2006). In the Vancouver School, the understanding of the phenomenon being investigated is constructed first through individual cases (steps 1-7), then as a whole (step 8): the 12-step process is cyclical (see Table 2 below). This makes the method different from a straight forward qualitative, inductive approach. Themes identified are thus strongly linked to the data (Patton, 1990) and not driven by analytic preconceptions or theoretical interest in the topic.

Table 2: The Vancouver School of Doing Phenomenology – 12 step process

First there is silence	Before entering a dialogue
Selecting dialogue partners	Selection of co-researchers
Participating in a dialogue	Data collection
Sharpened awareness of words	Data analysis -Deconstruction
Beginning consideration of essences	Coding
Identifying the essential structure of the	Construct of an analytic framework of the
phenomenon in each transcribed dialogue	phenomenon

Verification of the analytic framework with	Verification of the single case construction
the relevant research participants	with the co-researcher
Identifying essential structures of the	Construction of an analytic framework of
phenomenon of the study	the phenomenon
Compare the essential structure with the	
data	
Identifying the over-riding theme which	Interpreting the meaning of the
describes the phenomenon	phenomenon
Verifying the essential structure of the	
phenomenon with research participants	
Writing up the findings	

Sufficient sample size was achieved by moving back and forth between design and implementation to ensure congruence between question formulation, literature, recruitment, data collection methods, and analysis (Morse et al., 2002). Because of this, the sample consisted of participants who best represented or had knowledge of adherence to HAART thus ensuring efficient and effective saturation with optimal quality data. Further steps followed for validity or trustworthiness included four aspects: confirmability, credibility, transferability, and dependability (Lincoln & Guba, 1985). To enhance confirmability all information was recorded, an audit trail kept, and all relevant data were included in the final manuscript (Morse et al., 2002; Wolcott, 1990). Credibility criteria involved reviewing literature and working closely with supervisors and peer-researchers, obtaining expert opinions with critical feedback, and crosschecking my overall understanding of what was reported with the dialogue partners by taking transcriptions and interpretations to participants for validation. The combination of different methods (i.e., focus group and one-to-one interviews) helped search for consistency between data and gave a more rounded picture of the study (Farmer et al., 2006).

To build each participant's story at all stages of the research process, all ideas were considered and data closely listened to (Guba & Lincoln, 1981; Patton, 2002), setting aside previously held assumptions using a reflexive journal. In line with the Vancouver School, validation therefore became investigation, continually checking, questioning, and theoretically interpreting the findings (Halldorsdottir, 2000). The results may, however, not be generalized to all contexts, or indeed to all Aboriginal men, as the participants in this study were all from the DTES community in Vancouver. However, to allow for other researchers to determine the degree of transferability to similar situations (Trochim, 2006) information on research context, assumptions made, and sufficient quotations were recorded.

#### RESULTS

The essence of the phenomenon was characterized by five over-riding themes: (1) patient factors, (2) inter-personal factors, (3) support structures, (4) history of trauma/ residential school attendance, and (5) medication-related factors. Furthermore, secondary themes are organised under the five main themes (see Table 3 below).

Table 3: Factors that Influence Adherence to HAART

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

## **Patient Factors**

#### Psychological Factors

When discussing factors that may reduce their adherence, some participants indicated that during times of depression one is less likely to take his medication. One explained:

When I get into depression, I need supervision to make sure I take the pills, because when I fall into depression, feeling of, 'Poor me.' I stop taking the meds. I get depressed then anger comes out as a way of trying to control the depression and, I forget meds (Patient #2).

Alcohol and illicit drug use was a major factor voiced by 16 participants. Some indicated that they forgot to take their medication following a drug binge whilst others said that they prioritized taking illicit drugs over their medication when both were available:

[T] hey could be right in front of me whether I had to or what - for me, it wouldn't matter. The drugs would come first and the ARVs [HAART] would come last (Patient #16).

Respondents indicated that the fear of getting more sick or dying remained omnipresent in their lives with many being aware that adherence to HAART would give them the opportunity to live longer and healthier. One commented:

I know how fast I get sick and what it's like to feel that way because it's nothing I want to go through again - that's why I'm taking my medication (Patient #21).

A few respondents cited procrastination as a reason for poor adherence, one commented:

When I don't have a reason to get up in the morning, that's when I start, 'I'll take it later. I'll do this later'. Procrastinating and I never, nothing gets done (Patient #22).

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

I was too busy [trying to go eat]. I got up late and just didn't have time. When I finally got home I forgot all about it. It wasn't on my mind anymore. If I don't do it in the morning, I forget about it (Patient #2).

One respondent in the study cited memory loss as a significant factor leading to low adherence to HAART:

Sometimes I forget if I take them or like, sometimes I have this memory loss. It was really bad and I noticed I didn't have as much memory loss like before - like I'm trying to figure out why I lose my memory now, forgetful now and then, you know (Patient #8).

A few respondents believed that adherence to, and effectiveness of HAART depended on what state their spirit was in to begin with. One commented:

I grew up knowing my cultural traditional practices and to me I find that, if my spirit is low, I'll not take my medication, any kind of medication or medicines didn't work or they don't work as well (Patient #17).

#### Socioeconomic Factors

Some of the participants in this study stated having difficulty meeting their food and other needs:

Money too, that's a major issue on my brain...all the time. I spend more time seeking money, trying to provide myself with cigarettes and just the basic needs that I really don't have time to take any medications (Patient #24).

Some respondents who were homeless often had a distorted sleep pattern which led them to sleep through medication time or not remember if and when they last took their HAART. One commented:

Yeah, when I was homeless before I used to have a hard time because sometimes I don't sleep, and then when you finally sleep you sleep for days and so, that's another way how you miss meds too, ... because you forget (Patient #12).

## Other Factors

A good number of participants indicated that their knowledge of drug resistance and drug interactions helped them take their medication regularly:

When I found out I was affected, I quit drinking so my medications would work because if you drink and you take pills, they won't work (Patient #9).

One respondent, however, said that it did not really bother him if he missed some of his medication. He commented:

Even if I miss them for a week or two weeks, that resistance doesn't bother my system. When I go back and do a blood test my viral level is undetectable, my CD4 level is still up there, about 500. But most cases, I think the drug would not work, but it seems like it works for me maybe because I've used it for eight years - there's so much in my blood stream, my tissue, my body (Patient #12).

#### **Interpersonal Factors**

## Stigma and Discrimination

Most participants expressed their experience of stigma and discrimination and how these affected their adherence to HAART. One commented:

It happens quite a bit. Stigma down here. There's a lot of things out here to make a person angry. A lack of recognition for me as a human being, okay, that's one of the things that I sadly don't like at all. I hate it that they just, I'm just a tool. I don't have any connection in the community. I'm on the outside and so, I don't take medication (Patient #2).

## Patient-Care provider relationship

Some of the participants in the study, when asked whether their relationship with their care providers was a factor determining adherence to HAART, commented that how one is treated determines adherence:

You know what I think makes all the difference in the world in regards to health, especially for people in this area - is the caregivers - that if you go someplace for medical care and you're not treated with any kind of dignity or respect what are you going to feel like? I am not going to go back to that place (Patient #14).

## **Support Structures**

## Availability of and Access to Food

Access to food, as well as adequate nutrition, was cited by most participants as an important determinant of adherence to HAART:

I come here for breakfast and lunch and that gives me the get-up-and-go do all my stuff, or else I would just stay home. If they wanted to give me a whole bunch of medication just for 30 days, I probably wouldn't take them because I still have medication at my place where it's on the shelf and it's staying there. So I come in now and that's better (Patient #23).

## Staff and Friends' Support

Most of the participants indicated that support from care providers, fellow patients and friends improve their adherence to treatment. One commented:

I come here because I like the staff and everything, the way people help. And I like the way things are run and for my meds. I take my medication here. They help me keep up with my medication if possible. And they ask me why, sometimes when I do miss (Patient #10).

## Counselling

Most respondents in this study commented that counselling does improve adherence to HAART:

They help me to take my meds, get all the help I need. And the people like, I go see my Drug and Alcohol counsellor, they have all the help here for that. And I was seeing them for a while, until I got into a stable place where I didn't really have to see too much (Patient #3).

However, one explained that the community has to get involved otherwise counselling alone would not change anything:

He's the drug counsellor. There's a men's group that you can go talk at and maybe get some of your stuff out. But the problem is that most of the people don't want to do it because it doesn't change anything. Doing that doesn't change anything. You're still stuck with the original problem. It takes a bigger movement, and it's about people outside of the HIV community (Patient #2).

## Methadone Maintenance Treatment (MMT)

Five respondents explained that their access to MMT was associated with decreased heroin addiction and better adherence to HAART. One respondent explained:

I come here every day to get my methadone. So that was why they decided to bring the medications here too. So if I wasn't on methadone, maybe I would miss some days and that. But because I gotta come here, I'm lucky that I have that setting (Patient #9).

However, some participants thought that even though the MMT program is available, there is unfairness in the way it is provided. One commented:

I can't see why the health care system, like we're talking about pain medication, MMT, okay. They [doctors] say, 'Well we don't want to get you hooked on these drugs.' I'm already hooked on worse drugs. What's the difference? What makes me different than a 53 working male out there who gets these things? Why am I being told no? You know, when I'm asking you for your help and you say, 'No well we can't do that because you live downtown eastside.' That doesn't make sense to me (Patient #2).

#### Medication Pick-up routine and Outreach

Some patients revealed that their adherence to the HAART had been greatly facilitated when their medications were dispensed to them by health care professionals through outreach. One commented:

They helped me keep up with my appointments and they got the outreach workers here that come help me. Like, sometimes when I didn't make it here, the nurses here come out and they'd come check up on me and they make sure I take my meds (Patient #24).

Some patients were motivated to adhere to their antiretroviral regimens after receiving help and support from a pharmacy medication pick-up system. One commented:

Just the way I get them at the pharmacy every day. That helps me take them [medication] that way. If I was to do them on my own I wouldn't be able to do it. I like the way it's done. I come to the pharmacy first thing in the morning and I take them (Patient #4).

## Availability of Funding and Services/programs

Almost half of the respondents identified a lack of funding and services as a factor contributing to low adherence to HAART:

Proper services are needed. You see, if you don't access services, what's going to happen? You're just going to get sicker and possibly die (Patient #13).

## Aboriginal-centered Services and Practices

A few participants in the study, when asked whether there are other services that affect their adherence, expressed that their experiences with Aboriginal services played a big role in whether they took their medication or not. One commented:

They got traditional medicine there. So I go down every Tuesdays and Thursdays. Well, the way they do it, the way they sit in a circle, traditional medicine is like the Indian way, the Native way. And doing it that way helped me much better. I learned from other people doing it that way (Patient #4).

## History of Trauma/Residential School

Most participants said historic trauma had affected their adherence to HAART; however, their views were diverse.

#### Drug abuse

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

I guess so, in a way it does mentally, because I still think of it....emotionally and you feel, you think and it gives you pain and I guess in a reflex makes you do-- it made me into a alcoholic and drug addict because of that (Patient #1).

One respondent further explained that illicit drug use may be fuelled by a view that the practice was acceptable. He lamented:

I think why HIV isn't leveled out in Vancouver is because we've got an open drug scene all the way from Cambie to Main Street. I could look down, right, and do it right there. It's still more acceptable, more open and that's why it isn't come down - the HIV rate (Patient #7).

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

A few others said that historic trauma resulted in them having low self-esteem, self-blame, insecurity, fear, and resentment. One explained:

When a person doesn't feel worthwhile or have a reason to move forward in their lives, they stagnate. And like anything that starts to rot inside or stagnate, the human psyche doesn't want to stay still. It wants to love, to be part of something, to be one of the sheep in a herd. When they're segregated they just, like this, left through residential abuse, HIV, drug usage, being Native. Those things are all negative connotations that breed insecurity and fear, resentment. And the only thing we have in society to not feel that way is a chemical that makes you feel numb for a while (Patient #18).

## Other effects

A few respondents said historic trauma resulted in development of survival skills. One said:

But there's an upside to everything, is he's really....tough. He said to me, well we don't have anything to eat, 'well I spent lots of time where I didn't eat for five days when I'd run away' - so that's the upside - it makes you really tough. So it's not just one way, plus he's really smart at the street level, smarter than I am but tougher in a way, so (Patient #16).

#### **Medication-related Factors**

Respondents reported an association between medication-related factors and adherence to HAART. Many participants indicated that, because of pill burden, fit to lifestyle and eating patterns, complete adherence was a daunting task. One commented:

So, what I've gone from nothing to AZT mono therapy to 43 pills, 7 times a day where you've got to get up at 2 in the morning and take it and this one you can't take with food and that one you don't take with that one and just on and on and don't take grapefruit, to 3 pills a day all at once. I mean it's just remarkable - it's so easy now (Patient #12).

#### Side effects

Three participants indicated that medication side effects significantly contributed to their low adherence to HAART. One commented:

Even though my meds bother me, I can't keep my medication. I'm scared to take them now because they make me so sick. Like every time I take them I throw them back up and I'm sick through the whole night. I can't sleep. This has been going on a week now (Patient #4).

#### DISCUSSION

The results of this study are consistent with the literature in that all factors raised by participants have been widely discussed. This is shown in table 4 (below). However, previous literature has focused on single explanatory factors.

Table 4: Determinants of adherence linked with previous literature

Determinants	of Adherence	1
	Poor adherence	Improved adherence
Depressive symptoms	<ul> <li>Early discontinuance or non-adherence (Leserman et al., 2002; Simpson et al., 2006).</li> <li>Treatment refusal (Blumenfield, Milazo, &amp; Wormser, 1990).</li> <li>Poor motivation (Lyketsos et al., 1996; Nakiyemba et al. 2006).</li> </ul>	
Counseling		• Availability of appropriate counseling (Knobel, 1999; Zaric et al., 2008).
Active alcohol and drug use	<ul> <li>Reduced motivation or forgetfulness (Chandler, Lau, &amp; Moore, 2006; Sankar et al., 2007)</li> <li>Disruption of daily life activities (Hartel &amp; Schoenbaum, 1998).</li> </ul>	
Length and severity of illness	Undetectable viral loads (Buzón et al., 2010; El-Sadr et al., 2006).	<ul> <li>Acceptance of the illness and role of medication (Lewis et al., 2006).</li> <li>History of opportunistic infection, advanced disease or symptom severity (Bond &amp; Hussar, 1991; Singh et al., 1996).</li> <li>Knowledge of drug resistance (Green, 2004).</li> </ul>

	Poor adherence	Improved adherence
Competing priorities	<ul> <li>Procrastination (Conway, 2007; Westerfelt, 2004).</li> <li>Memory loss (Becker et al., 2004; Selnes, 2005).</li> <li>Food insecurity (Kleeberger et al, 2001; Newnham, 2005).</li> <li>Homelessness (Laws et al., 2000; Reback, Larkins, &amp; Shoptaw, 2003).</li> <li>Unemployment (Fong et al., 2003; Newnham, 2005).</li> </ul>	<ul> <li>Adequate nutrition knowledge and support (Gillespie &amp; Kadiyala, 2005; Ivers et al., 2010).</li> <li>Access to safe, affordable housing (Holtgrave &amp; Curran, 2006; Wolitski et al., 2007).</li> </ul>
Traditional beliefs and ceremonies		<ul> <li>Traditional beliefs on spiritual balance (McLeod, 2004; Montour, 2000).</li> <li>Participation in traditional ceremonies (McCormick, 1997; Poonwassie &amp; Charter, 2001).</li> </ul>
Stigma and discrimination	Psychological stress, self- destructive behaviour, low self- esteem (CAAN, 2004; Rintamaki et al, 2006).	
Historic trauma	• Destructive coping mechanisms, low self-esteem, sense of hopelessness (Barlow 2003; Craib et al., 2003).	Development of survival skills (Wesley-Esquimaux & Smolewski, 2004).
Relationships	Bad patient—care provider relationships (Simoni et al., 2003).	Good patient–provider or patient-significant other relationships (Emlet, 2006; Schneider et al., 2004).
Support services and funding	<ul> <li>Inadequate MMT program (Parkes, 2009; Spittal et al., 2007).</li> <li>Lack of funding and services (Van Dyk, 2008).</li> </ul>	<ul> <li>MMT program availability (DHHS, 2009; Hernández et al., 2009; Muga et al., 2004).</li> <li>Outreach intervention/ medication pick-up system (Berrien, 2004; Needle et al., 2005).</li> </ul>

	Poor adherence	Improved adherence
Medication-	Medication side effects (Duran	Simple drug regimen (Duran
related factors	et al., 2001).	et al., 2001; Kleeberger et al.,
		2001).

This study examines how these factors are interconnected and thus underscores the importance of addressing all factors that impact adherence to HAART together (see Figure 1). A deeper look shows a pattern of interconnectedness between factors. For example, forgetting medications is indirectly associated with homelessness (Patient #12) and secondary to either depression, being too busy (Patient #2), or memory loss (Patient #8). The same respondent (Patient #2) also says that stigma or discrimination, secondary to him being a drug addict, leads him to not take his medication or access MMT. He is also both depressed and a drug addict because of historic trauma. He then attends counselling but says that this alone does not change anything; he is still stuck with the original problem [drug addiction and drug availability on the streets (as reflected on by Patient #7)]. Patients #1 and #8 echo this sentiment stating that a personal history of trauma gives you pain and makes you a drug addict as you try to cope. Another example is that whether or not one goes to get medication depends on several competing factors: the availability of either food (Patient #23), a pharmacy medication pick-up program (Patient #4), or an MMT program (Patient #9) encourages one to take medication, whereas the easy availability of illicit drugs and the open drug scene (Patient #16) (also mentioned by Patient #7 above), unemployment and spending time looking for money (Patient #24) are competing factors to adhering to HAART. These connections are shown in Figure 2.

With respect to depression as a factor that lowered adherence, and given the chronic nature of HIV infection and the complicated treatment regimen, constant intrusive thoughts around the illness and treatment may increase stress and depressive symptoms in patients (Schonnesson et al., 2004). Also, the resultant decline in CD4 counts and disease progression may be due to the effect of depression on the immune system (Herbert & Cohen, 1993; Singh et al., 1996). Stress can also cause depression or vice versa, making it almost impossible to determine which has a more important role in affecting adherence (Salzano, 2003).

Figure 1: Interconnectedness between Factors (focus on low adherence).

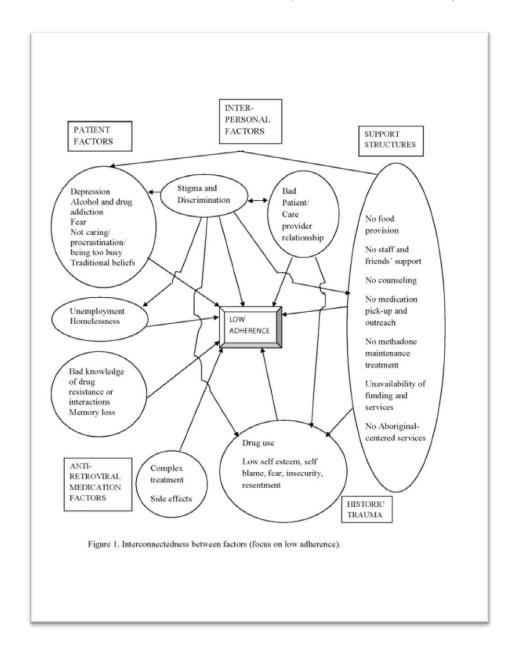
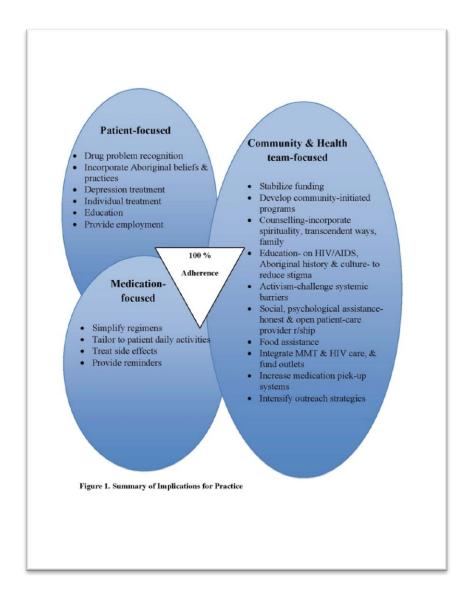


Figure 2. Summary of Implications for Practice



Forgetting medication could be secondary to reduced concentration after taking illicit drugs or drinking alcohol. Memory loss as a factor leading to low adherence could be secondary to HIV damage to brain cells. Memory loss secondary to HIV disease progression in patients may be wrongfully attributed to forgetting medication following drug or alcohol abuse. Such memory loss should not be misdiagnosed as this would mean missing an opportunity to delay progression by instituting measures, such as medication assistance, to ensure better HAART adherence. Also, even though low adherence can lead to increased mortality (Adler & Newman, 2002), the subsequent high rates of death of HIV/AIDS patients in previous literature could be a result of drug overdose (Milloy et al., 2010) and not secondary to memory loss or forgetfulness. However, the fact that a few respondents had a tendency to notice their viral loads were undetectable and that they

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were healthier is worrisome, because HIV monitoring indices may improve transiently despite sporadic adherence, reinforcing a patient's level of overall poor adherence whilst making the patient liable to development of drug resistance (El-Sadr et al., 2006). Furthermore, despite a strong and lasting suppression of HIV viremia resulting from HAART, if therapy is interrupted the replication of HIV resumes (Buzón et al., 2010). Patients who do not worry about missing medication may be expressing a lack of sufficient knowledge regarding HAART.

The lack of safe and affordable housing in the DTES needs particular attention. However, the housing situation is complicated as some shelter facilities in the DTES turn people away because of lack of space (Newnham, 2005), and people may not be willing to use these facilities because the shelter may be unclean or unsafe (Spaxman, 2009).

Most HIV/AIDS patients experience discrimination which further contributes to the disproportionate impact of HIV/AIDS on Aboriginal communities that already experience difficulty obtaining care for HIV-related illnesses (Strathdee et al, 1998; Wood et al., 2004). Discrimination could be associated with lack of knowledge about HIV/AIDS or insensitivity to Aboriginal cultures, traditions, and socioeconomic conditions, secondary to negative stereotypes about Aboriginal people (Larkin et al., 2007), and may be reinforced by power dynamics and other social problems. However, some may be engaging in illicit drug use, viewing it as an acceptable practice (Newnham, 2005). This compounds the problem, because despite expansions in the availability of MMT in BC, and its demonstration of successful opiate addiction treatment and HIV prevention (Gibson et al., 1999), physicians in public health clinics in Vancouver are unable to meet patient demand (Buxton, 2007; Mehrabadi et al., 2008).

Even though counselling may be provided, as shown in this study, optimal treatment of substance abuse may not be available when needed. There may also be problems with waiting lists and capacity (Spittal et al., 2007). Furthermore, having enough local resources to provide counselling may not be a reality for most Aboriginal communities, and Aboriginal clients may not have access to Aboriginal counsellors. The counselling provided may therefore not be culturally sensitive, unable to deal with spirituality or make sense of Aboriginal lifeworlds, and hence may not solve one's problem (Merali, 1999; Duran & Duran, 1995).

For some patients, the availability of traditional ceremonies and funding for programs are vital to adherence as shown in this study. This is also because less funding could result in increased HIV infection rates since, with fewer programs people could spend more time on the streets exposed to drug abuse and other risky behaviours. For Aboriginal people, participating in ceremony may foster integration and application of learned cultural

imperatives (Poonwassie & Charter, 2001; Régnier, 1995) that translate into appropriate behaviours that include staying away from illicit drugs and adhering to HAART.

Under medication-related factors, sustaining optimum levels of anti-retrovirals to suppress HIV replication and attaining therapeutic efficacy may be difficult, because HIV/AIDS patients often suffer from secondary opportunistic infections and other conditions such as depression, and may therefore have to take more medication to treat these (Day, 2003; Ng et al., 2000).

#### CONCLUSION

This study demonstrates how challenging it is for Aboriginal men who are HIV-positive patients to adhere to HAART and it also contributes to the field of HIV/AIDS research by providing a comprehensive scheme of themes that describe what affects their adherence. This study also suggests promising developments that have implications for research, practice and policy implementation. The themes generated from respondent interviews and focus group are distinct; however, they must not be seen in isolation. The implication is that in order to manage the problem of low adherence, one must consider all factors holistically.

The relationship between the experience of treatment, psychological distress, and other health issues needs to be addressed; assessing depressive symptoms closely in HIV patients with reduced adherence should be considered (Schonnesson et al., 2004). This would enable clinicians to diagnose depression or other causes of memory loss (Becker, 2004; Selnes, 2005) early and provide appropriate treatment which may lead to enhanced adherence to HAART.

The first step in provision of care and treatment for alcohol and drug abusers should be recognition of the existence of a drug problem. This should be followed by development of targeted interventions and the provision of services that respond to a patient's immediate and individual needs (Montaner & Volkow, 2010). Patients also need education on medication regimens, development of drug resistance (Kozal, 2004; Parsons et al., 2007), and the benefits of 100% adherence to HAART. Education of the general population and caregivers on Aboriginal history and culture may be imperative in the effort to reduce the impact of discrimination and promote better adherence to HAART (Link & Phelan, 2006; Rintamaki et al, 2006). Stigma and discrimination must continue to be challenged through activism from multiple forums. Care providers need to remain engaged with their patients, maintaining an honest and open relationship, and assisting them with both social and psychological issues, in efforts to promote better adherence (Ickovics & Meade, 2002; Ingersoll & Heckman, 2005).

Aboriginal community-initiated programs and services that reflect local community needs (McLeod, 2004; Montour, 2000) must be funded and promoted. Spirituality and transcendent ways of understanding the world need to be incorporated into modern ways of counselling (Poonwassie & Charter, 2001; Sue & Sue, 1990) in order to allow those who have experienced historic trauma to begin healing. Meaningful employment opportunities for APHAs should be made available to reduce the dependency on social service organizations for assistance. Coupled with provision of safe and secure housing, this could fix the problem of low adherence to HAART long-term in the resource-poor neighbourhood of the DTES as more and more people experience stable livelihoods (Aidala, et al., 2005; Kidder et al, 2008).

Food assistance should be integrated into HIV treatment and prevention programs and, each individual on HAART should be linked to a support mechanism that would ensure the availability of food on a daily basis. Integration of MMT and HIV care should be continued, more outlets funded, and the number of localized medication pick-up systems increased to help in adherence to HAART (Krüsi et al., 2009). Outreach strategies should be continued and strengthened as they are pivotal to improving HAART adherence. The use of simple treatment options involving compact once-daily regimens should be made standard practice. Provisions should be made for adjusting medication schedules to a patient's meal or daily program of activities. Furthermore, patients should be better educated about potential side effects and the need to cope with them timely. All implications for practice aimed at achieving an ideal situation of 100 percent adherence are summarized in Figure 2.

Finally, while the determinants found here provide an understanding of the intricacies and complexities of HAART adherence for these Aboriginal men, the results are from patients drawn mainly from the VNHS. Other types of patients (e.g.: youth, individuals on reserve etcetera) may have different determinants. This possibility may need to be researched in the future. The methodology and process adopted in this study clearly demonstrate the importance of relationship-building as an integral part of the research process. This is vital to research that seeks to examine the complexities of the daily lives of people.

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ESTABLISHED IN 2006 <u>www.caan.ca</u> 64

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