

Table of Contents

Introduction	1
Section 1: Aboriginal Community-based HIV/AIDS Research and Development	3
“Because we are Natives and we stand strong to our pride”: Decolonizing HIV Prevention with Aboriginal Youth in Canada Using the Arts.....	4
<i>Sarah Flicker, Jessica Danforth, Erin Konsmo, Ciann Wilson, Vanessa Oliver, Randy Jackson, Tracey Prentice, June Larkin, Jean Paul Restoule and Claudia Mitchel</i>	
Cultural Concepts of Care among Aboriginal People living with HIV and AIDS: A Study by the Canadian Aboriginal AIDS Network.....	24
<i>Charlotte Reading, Ryan Brennan & Renée Masching</i>	
Section 2: Dissemination of Results Findings.....	39
Perspectives of Canadian Inner City Aboriginal and Non-Aboriginal People Living with HIV and AIDS.....	40
<i>Payam Sazegar, David Tu, Doreen Littlejohn, Archie Myran</i>	
Section 3: Commentary.....	58
Getting the Canadian HIV epidemic to zero: Valuing Indigenous cultures through holistic research.....	60
<i>Earl Nowgesic</i>	
Section 4: Emerging Issues in Aboriginal Community-based HIV/AIDS Research	71
Positive Social Support and Mental Health among Two-Spirit and Heterosexual Aboriginal People Living with HIV/AIDS in Ontario.....	74
<i>Adam Beswick, Art Zoccole, Cate Dewey, Positive Spaces Health Places team, Nathan Lachowsky</i>	
HIV/AIDS, Colonialism and Aboriginal Youth in Canada: Implications for HIV Prevention Work	95
<i>Christine Smillie-Adjarkw, June Larkin, Sarah Flicker, Jean-Paul Restoule, Ruth Koleszar-Green, Kevin Barlow, Claudia Mitchell, Renée Masching</i>	
Call for Papers	113

Health Perspectives of Canadian Inner City Aboriginal and Non-Aboriginal People Living with HIV and AIDS

Payam Sazegar^{*1}, *David Tu*^{1,2}, *Doreen Littlejohn*², *Archie Myran*²

1. Department of Family Practice, University of British Columbia, Vancouver, British Columbia
2. Vancouver Native Health Clinic, Vancouver, British Columbia

CONTACT AUTHOR

Payam Sazegar MD CCFP, Clinical Assistant Professor, Department of Family Practice, University of British Columbia. (Mailing Address) Vancouver General Hospital, Willow Pavilion, 805 W 12 Ave, Vancouver, BC, V5Z 1M9; (phone) 778-840-8078; (fax) 604-675-2457; (email) payam@mail.ubc.ca

MEETING WHERE DATA WAS PRESENTED

Canadian Association for HIV Research (CAHR) Annual Conference; Vancouver; April 2009

ACKNOWLEDGEMENTS

Thanks to Dr. Victoria Smye for reviewing our research proposal and manuscript. Thanks to Dr. Jonathan Berkowitz for his help in the statistical analysis of the card-sorting data and to the staff at the Positive Outlook Program at Vancouver Native Health Society for helping organize the focus groups as well as providing the meeting space. Thanks also to Merck Frost & the Vancouver Foundation for their financial support of Vancouver Native Health Society, who covered the cost of honorariums for the focus group participants.

ABSTRACT

This mixed qualitative and quantitative study identifies HIV & AIDS related health challenges of people living in Vancouver's impoverished inner city, comparing Aboriginal and Non-Aboriginal participants. Twenty-six HIV positive participants took part in focus groups and were asked open-ended questions about health priorities in order to design a Self Management Support program. A total of 29 health priorities were identified and subsequently ranked by means of a card-sorting activity, with weighted rankings analyzed for each subgroup. Participants identified relevant solution strategies that included taking increased personal responsibility and use of peer supports. Participants also described an evolution of needs based upon their "phase" of coping with their HIV infection.

KEY WORDS: focus groups, HIV & AIDS, self management, health priorities, Aboriginal peoples, inner city

INTRODUCTION

Aboriginal people living in North America are disproportionately affected by HIV infection and evidence shows that once infected they are less likely to engage in effective care and more likely to die, with or without highly active antiretroviral therapy (HAART), compared to Non-Aboriginal Peoples (Miller *et al*, 2006; Wood *et al*, 2006; Lima *et al*, 2006). It has been shown that HIV positive Aboriginal patients suffer not only from higher HIV related mortality but also higher all-cause mortality (Martin *et al*, 2011). Vancouver's Downtown Eastside (DTES) neighborhood has a reputation for being "Canada's poorest postal code" where diseases of poverty like HIV & AIDS are highly prevalent and Aboriginals are unfortunately over-represented. Aboriginal injection drug users in Vancouver's DTES are becoming HIV positive at twice the rate of their non-Aboriginal injection drug using counterparts (Craib *et al*, 2003). In 2006, the proportion of positive HIV test reports attributed to Aboriginal people was 27.3% in provinces and territories reporting ethnicity information (Public Health Agency of Canada, 2007) even though Aboriginal people constitute approximately 4% of the Canadian population. Even though Aboriginal peoples have a higher incidence and prevalence of HIV infection compared to their Non-Aboriginal counterparts, these differences may only apply to the injection drug using population (Duncan *et al*, 2011; Wood *et al*, 2008). When individuals already marginalized in society by poverty and discrimination develop a stigmatizing condition like HIV infection they may experience what is known as a 'layering' or 'double burden of stigma' (Mill *et al*, 2009) contributing to poor health outcomes.

HIV is now recognized as a manageable chronic infection and the chronic care model (Wagner *et al*, 1999) has been used extensively in the management of numerous chronic diseases, including HIV (Swendeman *et al*, 2009). In order to address the inequities of HIV care for Aboriginal people, the Vancouver Native Health Society has developed a quality improvement initiative applying a chronic care model to HIV care for their Aboriginal and Non-Aboriginal clients (Tu *et al*, 2013). Part of this initiative was the creation of a patient Self Management Support program and this is the primary reason the study described in this paper was undertaken. Self Management Support focuses on assisting patients to overcome their specific health challenges and achieve their personal health goals, leading to improved health outcomes for patients infected with HIV (Inouye *et al*, 2001; Rueda *et al*, 2009). Effective implementation of such a program requires a thorough understanding of your population's unique HIV health challenges and an appreciation of the differences created by culture and societal factors.

Work done by Davis-Michaud *et al*. (2004) in the United States revealed that HIV positive patients have a broad range of HIV related health priorities and that discrepancies often exist between patient and physician goals of care. Although it is widely acknowledged that care for Aboriginal people needs to be tailored to the unique perspectives and priorities of Aboriginal people, in the area of HIV there is very limited knowledge in the medical literature describing what these priorities are. A study by Chou (2004) examining HIV self care strategies showed that racial difference was a predominant predictor for the use of self-care strategies. In this paper, we present results from a series of focus groups conducted in Vancouver that examined the HIV

health challenges of inner city people living with HIV, with a special focus on the Aboriginal population.

METHODS

Design

A mixed qualitative and quantitative design was used. Focus groups were used to allow participants to identify a range of HIV-related health challenges and to give insights into how these are impacting their lives. Informed written consent was obtained from all study participants, and ethics approval was received from the Providence Health Care Research Ethics Board. Two weeks after the initial data analysis, in a large group setting, a 20-minute Powerpoint presentation was given to focus group participants allowing them to offer feedback on the study findings to ensure the accuracy of these results.

Participants

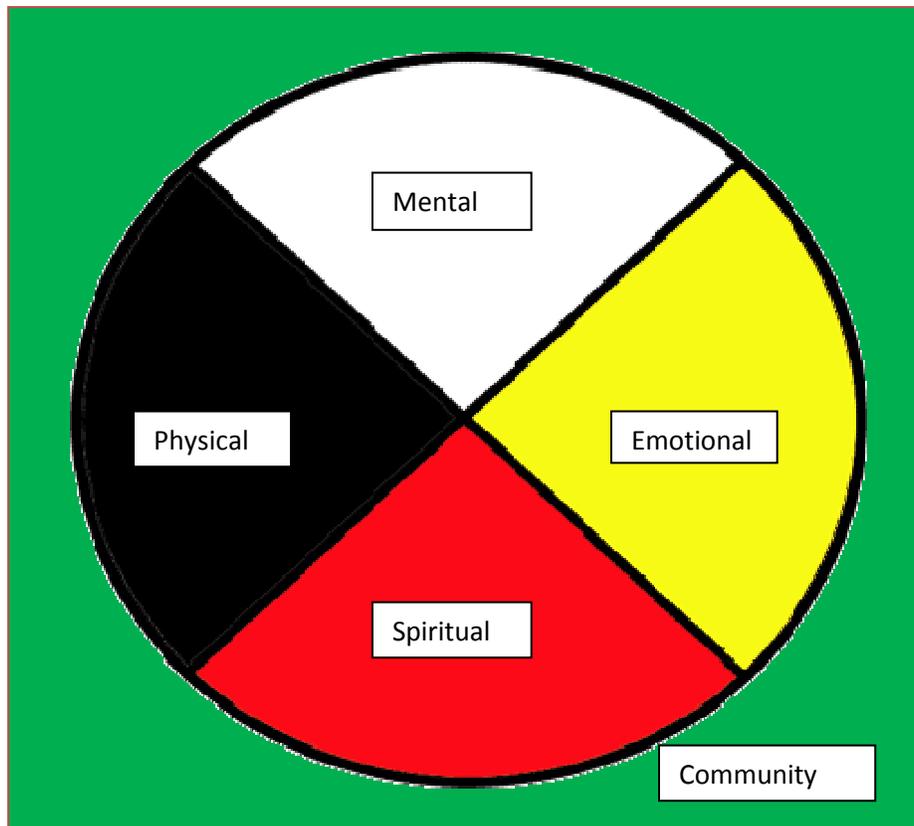
The study participants were drawn from the panel of HIV treatment patients at Vancouver Native Health Clinic (n=211), and were purposefully selected to be representative of the larger population. The inclusion criteria included fluency in English, HIV positive status and living in Vancouver's DTES neighborhood. A Peer Community Research Assistant outreached and received consent from a total of 31 participants, 26 of whom participated in the four focus groups held in April 2008. Participants were separated into groups based on gender and ethnicity to give four groups: Aboriginal Males (ABM), Non-Aboriginal Males (NABM), Aboriginal Females (ABF) and Non-Aboriginal Females (NABF). Participants were offered a \$20 honorarium and told they had to be "clean and sober" the day of the focus group – this may account for the five consenting participants who choose not to attend.

As the participants attended Vancouver Native Health Clinic for their HIV care, they were familiar with and agreeable to the use of the Medicine Wheel (**Figure 1**) in conceptualizing healthy living.

Data Collection and Analysis

Focus groups were conducted using open-ended questions regarding the challenges of living with HIV in the DTES and the changes required to make things better. The Medicine Wheel, a universal symbol of wholeness, is used by health care providers at Vancouver Native Health to help clients focus on character strengths they seek to develop and to help them reframe negative health challenges as positive health goals. Using this model of the Medicine Wheel, with its different colors, participants were encouraged to think about the five domains of living with HIV: Physical (Black), Emotional (Yellow), Mental (White), Spiritual (Red) & Community (Green) factors as shown in **Figure 1**.

Figure 1: The Medicine Wheel: Used as a model for understanding the domains of illness in HIV & AIDS where Physical (Black), Mental (White), Emotional (Yellow), Spiritual (Red) and Community (Green) Factors are all taken into consideration.

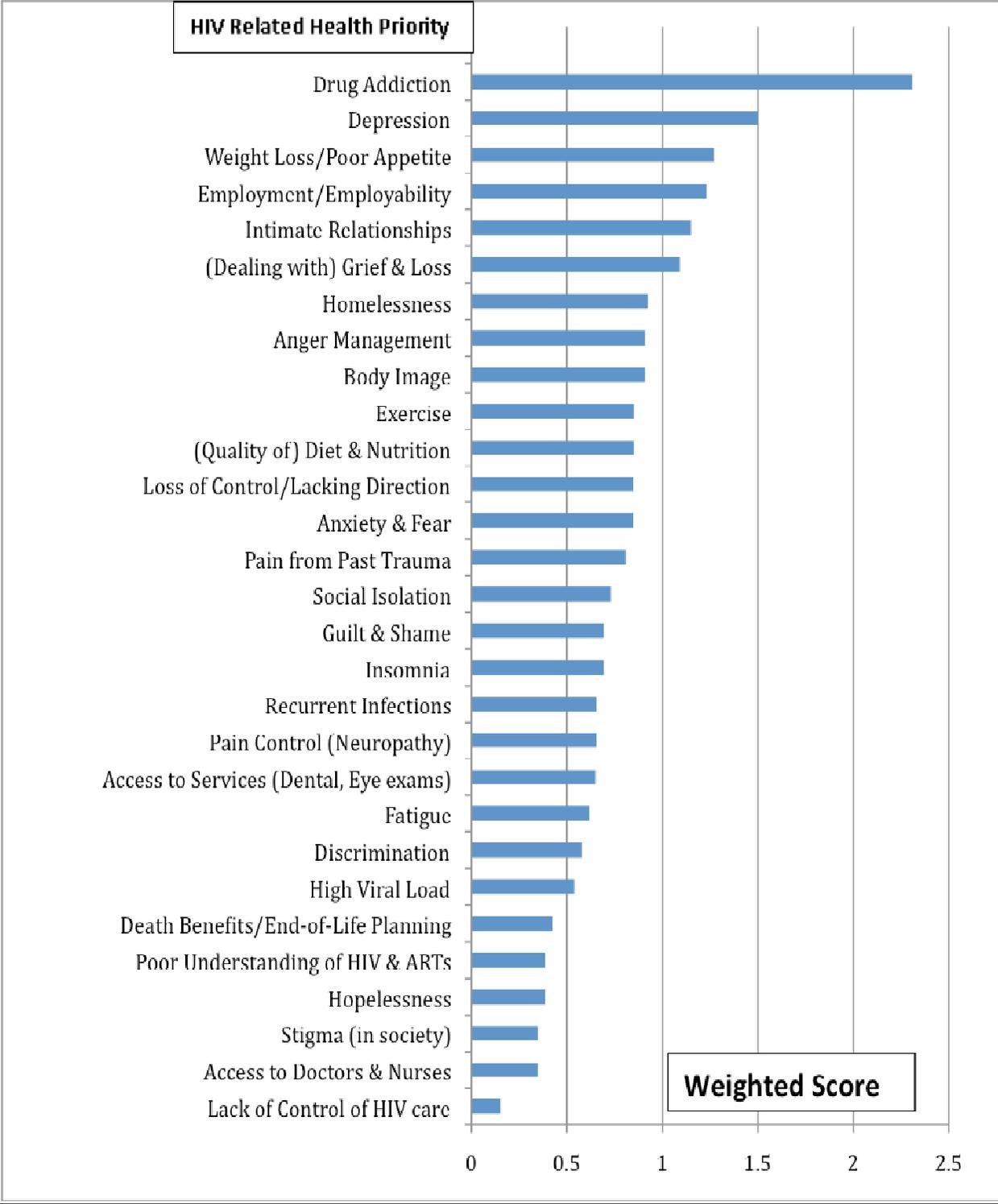


A total of 21 key words such as *Pain*, *Discrimination*, and *Depression* were brainstormed by the study authors and written on color-coded cards representing their respective domain prior to the focus group. Key words were based on the author's clinical experience treating HIV infection with additional key words being identified by focus groups participants. These flash cards were stacked into color-coded piles that participants had in front of them to serve as discussion prompts. New cards were prepared at the end of each focus group based on new discussion themes identified by the recorder. Focus groups were recorded and transcribed verbatim. Two facilitators and one recorder attended each focus group and debriefed after each group to record their impressions of the group dynamics and newly identified health priorities, for a total of 29 key words. Transcripts were analyzed by two independent reviewers and content coded with passages grouped according to emergent themes.

Following the focus group discussion each participant, under the supervision of a facilitator, was asked to prioritize the pile of health priorities and to organize the cards into two piles: the 12 more important, and the remaining least important (Group D). The non-group D pile was further subdivided into the 6 more important, and 6 less important (Group C). The non-group C or D

pile was further sub-divided into the 3 most important (Group A) and the 3 intermediate important (Group B). Weighted scores were assigned as follows: Group A (most important) = 3 points; Group B (intermediate) = 2 points; Group C (less important) = 1 point; and Group D (least important) = 0 points. For each group, weighted scores for each individual card were calculated by dividing the total score by the number of participants in the group. Additionally, we calculated the overall weighted score for each card by dividing the total score for all participants by the number of participants ranking the card to identify the top health priorities in our study population (**Figure 2**). Statistical significance was defined as p-value 0.05 or lower based on the t-test. Other than participating in the focus groups and affirming the study findings in the large group presentation, the participants did not have any other role in the study.

Figure 2: Overall Ranking of HIV Related Health Priorities: The overall Weighted Score for each Health Priority card was calculated by dividing the total score for All Participants by the number of participants ranking the card (N=11-26) to identify the Top Health Priorities in our study population.



RESULTS

Participants

A total of 26 participants took part in one of four focus groups: ABM, NABM, ABF and NABF. Demographic characteristics of the participants are shown in **Table I**. The groups were comparable with respect to baseline characteristics of age, employment status and duration of HIV infection. All participants were adults who were either on HAART or had been in the past.

Table I: Participant Characteristics

	Number of participants	Age, mean (range)	Employment Status		Years since HIV diagnosis, mean (range)
			Unemployed	Part Time	
ABM	6	44 (37-47)	6	0	10 (7-13)
NABM	9	46 (33-53)	8	1	9 (2-13)
ABF	7	38 (23-47)	5	2	7 (3-11)
NABF	4	41 (32-51)	4	0	8 (5-12)

Ranked Health Priorities

The top ranked priorities for all four groups are presented in **Table II**. The focus groups participants, as a whole, attached greater importance to psychosocial factors such as *Depression or Drug Addiction* over physical issues such as *Access to Doctors & Nurses* and *High Viral Load*. Collectively, the top 7 health priorities, in descending order, were: *Drug Addiction, Depression, Weight Loss, Employment, Intimate Relationship Difficulties, Grief & Loss* and *Homelessness*. During these card-sorting exercises, the facilitators guided the participants to reframe their health priorities in a positive light. For example, *Homelessness* was reframed as the desire to have stable housing.

Table II: Top Seven Priorities for Each of the Four Focus Groups: *Health Priorities are ranked by Weighted Score for each card in descending order.*

	Total	Aboriginal Men	Non-Aboriginal Men	Aboriginal Women	Non-Aboriginal Women
#1	Drug Addiction	Drug Addiction	Drug Addiction	Drug Addiction	Drug Addiction
#2	Depression	Guilt & Shame	Employment	Weight Loss/Poor Appetite	Loss of control/Lack direction
#3	Weight Loss	Pain from Past	Intimate	Anxiety & Fear	Depression

		Trauma	Relationships		
#4	Employment	Employment	Depression	Depression	Social Isolation
#5	Intimate Relationships	Pain & Neuropathy	Access to Services	Homelessness	Grief & Loss
#6	Grief & Loss	Depression	Quality of Diet & Nutrition	Intimate relationships	Body Image
#7	Homelessness	Social Isolation	Exercise	Insomnia	Anger Management

A limited number of differences were observed between the Aboriginal and Non-Aboriginal participants as described in **Table III**. Aboriginal participants seemed to attach greater importance to dealing with *Guilt & Shame* ($p=0.028$), *Anxiety & Fear* ($p=0.007$) and *Pain from Past Trauma* ($p=0.047$). However, statistically significant differences were not observed between Aboriginal and Non-Aboriginal patients in most of the 29 health priorities. New issues arising in the focus group discussion with NABM included *Quality of Diet and Nutrition*, *Intimate Relationships* and (having more) *Exercise*. Even though these new priorities were included in the card sort and ranked highly by the NABM group, we cannot make comparisons to the ABM group as it took place prior to this group and thus didn't have an opportunity to rank or discuss these health challenges.

Table III: Comparison of Aboriginals and Non-aboriginals on Individual Items: This table includes all items for which significant differences were found between Aboriginals (AB) and Non-Aboriginals (NAB), where statistical significance is defined as a p-value <0.05 on the t-test.

Health Priority	AB or	N	Mean Weighted		P-Value (t-test)
	NAB		Score	SD	
High Viral Load	AB	13	0.08	0.28	0.014
	NAB	13	1.00	1.23	
Recurrent Infections	AB	13	0.31	0.86	0.095
	NAB	13	1.00	1.16	
Guilt & Shame	AB	13	1.15	0.99	0.028
	NAB	13	0.38	0.65	
Anxiety & Fear	AB	13	1.38	1.12	0.007
	NAB	13	0.38	0.51	

Pain from Past					
Trauma	AB	13	1.23	1.3	0.047
	NAB	13	0.38	0.65	

A couple gender differences were observed. When we compare the overall data of males (n=15) and females (n=11) we found that Men ranked *Employment* significantly higher (mean 1.27 for Males and 0.64 for Females, p=0.02) and women ranked *Fear & Anxiety* significantly higher (mean 0.53 for males and 1.36 for females, p=0.03). No other statistically significant gender differences were noted.

There were 3 new issues arising in the Women’s focus groups were: *Grief & Loss*, *Body Image* and *Anger Management*. We were not able to compare these new issues to the male groups, who didn’t have a chance to rank these issues as their group preceded this one. These new topics were brought up in ABF group and no additional themes (other than the 29 listed in **Figure 2**) were explored in the subsequent NABF group. Between the two female groups, we did not observe any differing views on these health priorities in the focus groups nor did we observe any statically significant difference in the weighted scores for these three priorities (data not shown).

Emergent Themes

The emergent themes, based on the conceptual framework of the Medicine Wheel, were identified in the transcripts by two independent reviewers and have been organized below into three different phases of coping with HIV infection, as proposed by the model in **Figure 3**. This model was presented to the focus group participants in the large group meeting that followed the focus groups and was received well.

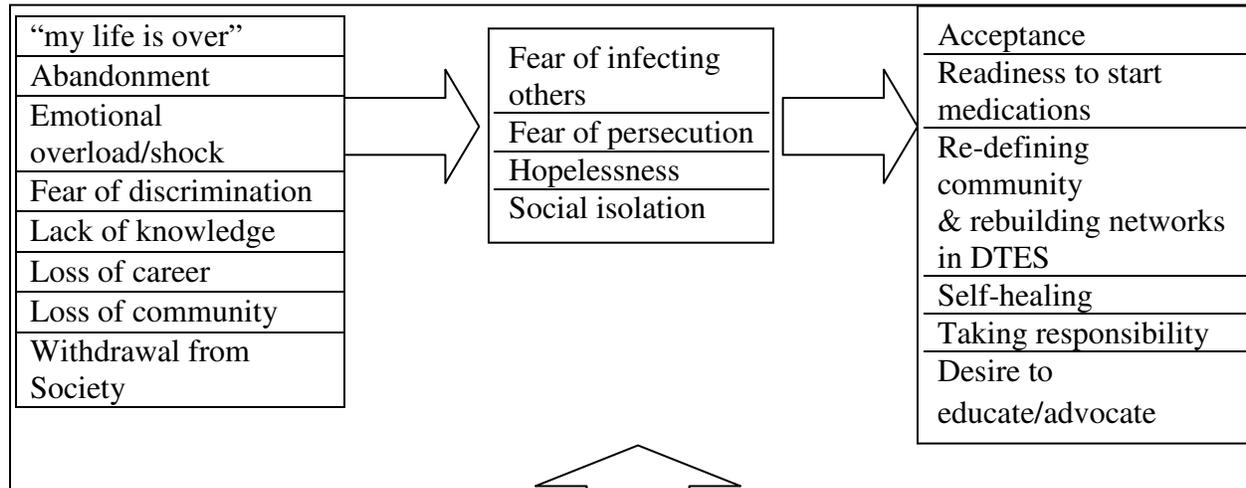
Figure 3: A Model of Phases of HIV illness as discussed by focus group participants:

Phases of Coping with HIV illness

Phase 1: Shock & Loss

Phase 2: Scared & Alone

Phase 3: Acceptance & Healing



INTERVENTIONS (Solutions & Resources)	Phase
Peer counseling in early time of diagnosis to mitigate shock and awe	1
<i>First Response Strategy</i> with team approach to breaking bad news	1
Patients as resources and positive examples	1 and 2
Professional counseling	2 and 3
Grief & Loss Counseling	ALL
Recreational outings to improve fatigue/insomnia	ALL
Ongoing Education sessions about HIV and ARTs	ALL
Maintaining a Positive Attitude	ALL
Medications (including ARTs) for insomnia/fatigue/wt loss/appetite	ALL
Learning to accept Personal Responsibility for Self Care	ALL
Compassion Club (Medical Marijuana) for nausea/appetite	ALL
Support from Organizations/Community Advocates	ALL
General education of the community to reduce stigma/discrimination	ALL
“Finding a Spiritual Path”	ALL

When questioned about the need for counseling and education, a recurring theme was that at the initial time of diagnosis patients go into an “Emotional Shock” or, as others said a “Spiritual Shock,” rendering them unready to learn new information or to seek out professional help. However, participants in all groups stated they would have been open to seeing a peer in this initial phase – “someone who has the disease” and is living a happy and healthy life despite their HIV diagnosis. There was a general plea for some form of ‘First Response Strategy’ where the physician has some sort of counselor or peer support person in the room or nearby when breaking the bad news of an HIV positive diagnosis. As someone in the NABM group said:

“Nobody thinks that I am positive because of how I look. Can you imagine that? I’m not skinny anymore, I’m not sick all the time anymore...if you can see someone who is positive looking [and] healthy because they accessed what is available to them down here, that does a lot of wonders”

In the focus groups, the power of a positive example and the role of peer support were deemed to be of high value. According to participants, 3 distinct roles for peers were identified: peer counseling, peer support (a ‘buddy system’) and peer education. When the participants met in the large group setting 2 weeks after the study to give feedback, they affirmed the accuracy of the study’s findings and underscored the importance of peer mentors and supports. For these reasons, it was decided that future quality improvement initiatives in our clinic population focus on the importance and effectiveness of peer coaches (D. Tu, personal correspondence). Finding a supportive and caring environment outside the DTES was noted to be a significant challenge for patients wanting to leave the drug-stricken area in hope of becoming “clean” from drug use. As one Aboriginal woman in the focus group tearfully spoke: “Sometimes I want to go home but my family don’t understand.” For patients who are not originally from the DTES neighborhood, which is the majority, returning to their home community can be very difficult. Social isolation also poses a challenge to those hoping to “break the cycle of transmission” and educate others about the realities of HIV, whether it be in the DTES or in their home communities. Fortunately, all groups underscored the role of peer supports and mentors as a possible solution strategy.

In all four focus groups, participants stated that they remember and are keen to know their numbers like “CD4 count” and “Viral Load” as well as the implications of these counts. There was perhaps less knowledge about how Antiretrovirals work. Though many participants stated they were satisfied with their knowledge of HIV and Antiretrovirals, a few in the ABF group emphasized the importance of continuing education and the need for it to be ongoing because they will not always remember the important information.

In later phases of coping with their HIV, participants from all groups described some degree of personal resilience and acceptance of their illness. Along with this comes a desire to advocate for others and to become a positive example. As one Aboriginal women said:

“I want to educate up North because they still think if you tested HIV and you’re positive, it’s a death sentence. They don’t know how far advanced its come, how much help there is.”

Excerpts from the transcripts describing some of the challenges of living with HIV are presented in **Table IV**.

Table IV: Selected Quotes from focus group discussions: Themes have been categorized by the 5 domains of the Medicine Wheel: Physical, Mental, Emotional, Spiritual and Community.

Theme	Group	Quote
Emotional: overload	Aboriginal Male	“I think maybe that, well, when people first contract HIV, they kind of go into shock. At least I did. You kind of go into a spiritual shock, an emotional shock, you don’t know what to do. “
Emotional: shame	Aboriginal Male	“It takes a lot of years to get over the shame of catching this disease, I’m still uptight about that, I don’t like telling people about it, so I chose to socially isolate myself. I have no recourse.”
Physical: appetite	Non-Aboriginal Male	“when I quit taking the pills [ARTs] for a year I was hardly eating but then I got back on the pills and, now, I find some nights I eat 3 full meals before I go to bed”
Spiritual: drug addiction	Non-Aboriginal Male	“The thing is, say, if you wanted to get clean...getting into a Detox is next to impossible sometimes...That’s what I find. Every time I do there is a 3 week wait and by then you basically say ‘the heck with it’ because its such a long wait”
Community: loss of friends and stigma	Non-Aboriginal Male	“Personally, when I first found out [HIV positive] I lost a heck of a lot of friends because they figured I was like...They didn’t want to be around me, they didn’t want to touch me, they didn’t even want to shake my hand for crying out loud”
Community: stigma, discrimination, lack of access to health care	Aboriginal Female	“Down there [Indian Reservation] it is social isolation, access to doctors and nurses, discrimination and lack of knowledge period. ..and nobody wants to talk about it [HIV] because they’re so stigmatized. Just saying you have Hep C, people are scared to sit in the room with you.”
Physical: positive feedback, importance of self care	Aboriginal Female	“My doctor put me on the anti-virals and I freaked out because everyone told me I’d be sick 4-6 weeks, the side effects, diarrhea, the sickness, hang in there and it’ll be OK. Well not only did I have no side effects, my energy level increased, its almost back to normal, my appetite increased and I went from being like 98 lbs to my regular weight which is normally 125-126. My first set of cocktails were so successful I’m now undetectable and my CD4 is 687.”
Community : resilience to discrimination	Aboriginal Female	“There is discrimination out there but I don’t put up with it. I stand my ground. If I let them climb all over me then I wouldn’t be sitting here today.”
Spiritual: drug addiction	Non-Aboriginal Female	“I got down on my hands and knees and I begged the Creator, you help me get my ass off of it and I’ll keep my ass off of it. And I still don’t know today. It must have been my time because, little by little,, it took 2 months before I could stand before someone who was using and not want it anymore”

Community: discrimination and stigma	Non- Aboriginal Female	“I fell the biggest challenge is just being accepted the same way. I mean people didn’t want my clothing, they didn’t want to stay overnight at my house, they really made me feel uncomfortable...like way back when they had Leprosy and they were put away. I felt like I was a Leper or something”
Mental: Acceptance, personal resilience	Non- Aboriginal Female	“I’m not embarrassed to tell people I am positive now. If they don’t want to talk to me after that then ‘you know what, hit the road. I don’t need you’...I tell everyone: ‘this is me, take it or leave it’ ”

DISCUSSION

The purpose of the Medicine Wheel in this study was to stimulate thought about goals and values that matter to our clients, thereby allowing customized personal action plans that engage them as proactive participants in their healing journey. The most significant HIV related health problems faced by the inner city population are a mix of physical, mental, emotional, spiritual and community issues. Hence, a patient-centered approach to HIV care needs to consider all these facets and how to build character strengths in each domain. Drug addiction and depression were the leading problems in all groups. It is interesting that patients did not place a higher rank to physical factors such as avoiding *High Viral Load* and *Recurrent Infections*, which are often the treating physician’s top priorities. Although there are a limited number of differences between Aboriginal and Non-Aboriginal participants there are many more similarities between these groups in terms of health priorities. Our focus group analysis allowed us to generate a model for understanding the phases of HIV infection experienced by our clients and identified the appropriate timing of deployment for specific solution strategies (**Figure 3**). When presented to the study participants, there was consensus and support for the use of this model.

A recurring theme was the need for peer support and peer counseling in the self management of HIV illness. It is worth noting that very few people in this study population have ever been to a registered clinical counselor or psychologist. In terms of coping mechanisms, participants admitted they have a tendency to turn to drugs, alcohol and peers in times of difficulty—its their comfort zone. Although participants stated they would be open to seeing a clinical counselor to learn new coping tools, their lack of experience may render them unable to appreciate its value in treating underlying issues contributing to their foremost health challenges, such as *Drug Addiction*. That being said, peer counseling at the time of initial diagnosis and a buddy system to help patients remember appointments and such had very high perceived value among the study participants. Given the importance attributed to peers, both peer-based and medical professional-based self management training has been made available to clients at Vancouver Native Health Clinic (D. Tu, personal correspondence). There is clearly a role for expanded access to mental health counseling and other social supports in the course of the illness.

The power of a positive role model was repeatedly stressed. This is perhaps one of the largest untapped resources because there are many individual HIV success stories in the DTES neighborhood and knowledge of these can mitigate the initial ‘shock’ of a positive diagnosis by letting people know they too can be healthy, productive and vibrant despite HIV, instead of preconceived notions that they will get sick, be a burden to their family and then die.

Although *Stigma* and *Discrimination* were spoken of as concerns in all focus groups, they were not ranked as highly in terms of how much they mattered to the participants (**Figure 2**). In the focus group discussions, participants discussed that these factors are major issues if and when they travel outside of Vancouver's DTES neighborhood. The fact that the study participants reside and socialize in the DTES, where they describe the existence of a strong sense of community and greater homogeneity, likely explains the low rank of this item as a health priority. However, participants also described stigma being a factor making them less likely to return to their previous or home communities. The development of personal resilience to the discrimination was spoken of in all the groups by patients who have had the illness for a number of years.

One limitation of this study was the relatively small sample size, which may explain why the quantitative detection of significant differences was not observed for many health priorities. While it is possible that the large number of health challenges examined increased the risk of chance differences, all of these challenges can be features of the illness experience in HIV & AIDS and need to be considered in all clients. Participants were instructed to rank the cards based on how important each health priority was to them personally; as many of the participants have been stable on antiretroviral treatment, they may rank physical or medical factors lower because they are no longer active issues in their lives.

The gender differences observed, with males ranking *Employment* higher and females ranking *Anxiety & Fear* higher, also merit consideration by front-line medical providers caring for these populations. Additionally, the female focus groups identified new health priorities such as *Body Image* but, due to the earlier timing of the male focus groups, gender differences could not be ascertained for these. However, all the issues mentioned in the focus groups need to at least be considered in the future development of Self Management Support resources for the inner city Aboriginal and Non Aboriginal population infected with HIV.

Like any ethnographic study it is difficult to extrapolate the findings of this study beyond the context of the participant's lives so the results may not be generalized to the entire Canadian Aboriginal and Non-Aboriginal population. But, as the majority of Vancouver's DTES residents, including the study participants, are not originally from Vancouver and represent many regions of Canada, the study sample is likely a reasonable representation of the Canadian HIV positive inner city population engaged in health care. Hence, the authors feel it is important that patient Self Management Support programs targeting HIV positive Aboriginal peoples probe for the HIV related health issues discussed in this study. The net result of this could be the provision of higher quality, cost-effective and patient-centered care for those infected by HIV.

The findings of this study have, in fact, been used by Vancouver Native Health Society to guide quality improvement interventions in HIV care. One outcome of this was the creation of a Patient Self Management Support module for health care practitioners working in Vancouver Coastal Health Authority to assess qualitative indicators in HIV treatment. Another outcome was a follow-up study comparing the effectiveness of peer coaches to health professionals in the

implementation of this Self Management Support module (D. Tu, personal correspondence). The different roles identified for peer mentors has important policy and practice implications for implementing effective HIV quality improvement initiatives targeting both Aboriginal and Non-Aboriginal peoples.

CONCLUSION

The results of this study provide a better understanding of health issues facing Aboriginal and Non-Aboriginal people living with HIV & AIDS in Vancouver's DTES and suggests a possibly hierarchy for their HIV related health challenges, as well as their preferred solution strategies. The spectrum of health issues for those living with HIV & AIDS is diverse, and this study reinforces that culture is an important factor in people's experience of disease, especially a stigmatized illness like HIV & AIDS. Appreciation of the diverse biopsychosocial issues affecting Aboriginal clients can help strengthen Self Management Support programs, thereby reinforcing character strengths, promoting healthy behaviors and greater patient satisfaction. Awareness of how patterns of needs and solution strategies change over time, and how these may differ from caregiver priorities, can help engage and empower patients by tailoring treatment plans to their specific needs. Awareness of these similarities and differences, as well as the preferred solution strategies, will be useful for HIV & AIDS program implementers seeking to improve health outcomes for the Canadian Aboriginal and Non-Aboriginal inner city population infected by HIV.

REFERENCES

- Chou, F.Y. (2004). Testing a Predictive Model of the Use of HIV/AIDS Symptom Self-Care Strategies. *AIDS Patient Care and STDs*, 18(2), 109-117.
- Craib, K.J.P., Spittal, P.M., Wood, E., Laliberte, N., Hogg, R.S., Li, K., . . . Schechter, M.T. (2003). Risk factors for elevated HIV incidence among Aboriginal injection drug users in Vancouver." *Canadian Medical Association Journal*, 168(1), 19-24.
- Davis-Michaud, M., Yurk, R., Lansky, D., Asch, S., & Wu, A.W. (2004). Quality care for people with HIV/AIDS: patients' perspectives. *HIV Clinical Trials*, 5(6), 406-415.
- Duncan, K.C., Reading, C., Borwein, A.M., Murray, M.C.M, Palmer A, Michelow W, . . . Hogg RS (2011). HIV Incidence and Prevalence Among Aboriginal Peoples in Canada. *AIDS and Behavior*, 15(1), 214-227.
- Inouye, J., Flannely, L., & Flannely, K.J. (2001). The Effectiveness of Self-Management Training for Individuals with HIV/AIDS. *Journal of the Association of Nurses in AIDS care*, 12(5), 71-82.
- Lima, V.D., Kretz, P., Palepu, A., Bonner, S., Kerr, T., Moore, D., . . . Hogg, R.S. (2006). Aboriginal status is a prognostic factor for mortality among antiretroviral naïve HIV-positive individuals first initiating HAART. *AIDS Research and Therapy*, 3(14), 1-9.
- Martin, L.J., Houston, S., Yasui, Y., Wild, T.C., & Saunders, L.D. (2011). All-cause and HIV-related mortality rates among HIV-infected patients after initiating highly active antiretroviral therapy: the impact of Aboriginal ethnicity and injection drug use. *Canadian Journal of Public Health*, 102(2), 90-96.
- Mill, J., Edwards, N., Jackson, R., Austin, W., MacLean, L. & Reintjes, F. (2009). Accessing Health Services While Living with HIV: Intersections of Stigma. *Canadian Journal of Nursing Research*, 41(3), 168-185.
- Miller, C.L., Spittal, P.M., Chan, K., Montaner, J.S.G., Schechter, M.T., & Hogg, R.S. (2006). Inadequacies in Antiretroviral Therapy use Among Aboriginal and other Canadian Populations. *AIDS Care*, 18(8), 968-976.
- Public Health Agency of Canada. (2007). HIV/AIDS Among Aboriginal Persons in Canada: A Continuing Concern. HIV/AIDS Epi Updates. Ottawa, Ontario: PHAC.
- Rueda, S., Park-Wyllie, L.Y., Bayoumi, A., Tynan, A.M., Antoniou, T., Rourke, S. & Glazier, R. (2009). Patient Support and Education for Promoting Adherence to Highly Active Antiretroviral Therapy for HIV/AIDS (Review). *Cochrane Database of Systematic Reviews*, Issue 1.

- Swendeman, D., Ingram, B.L., Rotheram-Borus, M.J. (2009) Common Elements in Self-Management of HIV and Other Chronic Illnesses: an integrative framework. *AIDS Care*, 21:1321-1334.
- Tu, D., Belda, P., Pedersen, J.P., Valle, J. & Tyndall, M. (2013). Adoption of the Chronic Care Model to Improve HIV Care for Inner City Aboriginal Peoples. *Canadian Family Physician* (in process).
- Wagner, E.H., Davis, C., Schaefer, J., Von Korff, M., & Austin, B., (1999). A survey of Leading Chronic Disease Management Programs: are they consistent with the literature? *Managed Care Quarterly*, 7(3), 56-66.
- Wood, E., Kerr, T., Palepu, A., Zhang, R., Strathdee, S.A., Tyndall, M.W., . . .Hogg, R.S. (2006). Slower uptake of HIV antiretroviral therapy among Aboriginal injection drug users. *Journal of Infection*, 52(4), 233-236.
- Wood, E., Montaner, J.S.G., Li, K., Zhang, R., Barney, L., Strathdee, S.A., . . . Kerr, T. (2008). Burden of HIV Infection Among Aboriginal Injection Drug Users in Vancouver, British Columbia. *American Journal of Public Health*, 98 (3), 515-519.