HIV+ABORIGINAL WOMEN SPEAK OF EXPERIENCE AND STRENGTH IN A NORTHERN CONTEXT

by

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Abstract

Aboriginal women living with HIV in the North have a unique perspective regarding helpful and useful services as well as painful experience concerning gaps in services. This research examines the responses of eight Aboriginal women in this regard and, additionally, invites them to identify life factors, which have been particular sources of strength. Using an open interview method via snowball sampling, the women were asked about services they found most helpful, resources that they thought were missing and to identify personal strengths contributing to their optimism and survival.

A systematic thematic analysis of the interviews resulted in five major themes: support, resources, identity, northern obstacles and strengths. The analysis also illuminated the reality that the women feel very supported and cared for by existing services that have proven to be incredibly valuable to their everyday lives. Follow up recommendations include: maintaining and increasing crucial services, continuing to lobby for increased funding, adding courses specific to HIV and AIDS to schools of social work curriculum and highlighting the realities of living with HIV and AIDS in a northern context.

TABLE OF CONTENTS

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DEDICATION

I sincerely wish to acknowledge the contributions and risks taken by the participants in this study. Without the strength, creativity, joy and resilience of the participants this work would not have the intensity of meaning and congruency that is apparent in this product. This work is dedicated to these women and to my family. My mother and father have been tremendously supportive and without their wisdom to lean on during the last leg of this journey I would still be writing my proposal. To my children, Madison, Elijah and Georgia: you continue to inspire me with your joy, creativity, love and playfulness. To my Grannie: you are a wise woman that walks with the goddesses and I can only hope to bring to other people the love, intelligence and compassion that you bring to all that have the privilege of experiencing that which is you. I have also been very fortunate to walk this earth surrounded by the love of my partner. I have had incredible depth of meaning in my life and I will continue to learn and grow from this beauty that is shared. Strength and absence of fear have shown me what it means to stop running.

GLOSSARY

Aboriginal: In the context of this study the term Aboriginal will refer to status, non-status, Métis, and Inuit women of Canada, recognizing however that many Aboriginal people rightfully describe or identify themselves otherwise.

Colonization: In describing colonization the United Nations stated "the subjection of peoples to alien subjugation, domination and exploitation constitutes a denial of fundamental human rights, is contrary to the United Nations Charter, and is an impediment to the promotion of world peace and cooperation" (United Nations, 2005).

Cultural Studies: "A field of inquiry that takes as its subject matter the culture-making institutions of a society and their productions of meaning. Interpretive studies examine the problematic lived experiences shaped by those culture-making institutions" (Denzin, 2001, p. 157).

Decolonization: "...steps should be taken to unconditionally transfer all powers to the trust and non-self-governing territories so that they might enjoy complete freedom and independence" (United Nations, 2005).

HIV: The virus that causes acquired immune deficiency syndrome (AIDS); it replicates in and kills the helper T cells.

Performance Ethnography: Performance ethnography uses the idea of performance (everyday life) as both a means to understand and a method to practice (Denzin, 2003).

Polyvocality: "Researchers should be conscientious that they are not studying a lived reality but many" (Saukko, 2003, p. 20).

Positivism: A doctrine that states that the only authentic knowledge is scientific knowledge, and that such knowledge can only come from positive affirmation of theories through strict scientific method, refusing every form of metaphysics (Creswell, 2008).

CHAPTER ONE: INTRODUCTION

Purpose

Aboriginal women living with HIV in the North face a significant number of barriers that are a direct result of the legacy of colonization. They are rarely given credit for the strength and resiliency with which they render their lives and struggles. In addition to carrying out effective, respectful research, this project intended to create a space where Aboriginal women living with HIV could contribute their voices to a greater understanding of the realities for themselves, and women like them in the North. By creating a sense of safety, I hoped to inspire the women to talk of their strengths, learnings and lives. In the intervening years, since this project began in 2006, other researchers have also seen the gap and have begun contributing to the empowerment of women regarding their HIV/AIDS experiences. I am excited to make this contribution in solidarity with Aboriginal women and their researcher/allies.

Research with indigenous peoples illustrates how "hard" sciences and the positivistic paradigm have contributed to the appropriation of culture, lands, voices and entire populations (Smith, 1999). I have a passionate desire to name the connection between HIV and the perpetuation of colonization and to provide a forum for Aboriginal women to reflect their experiences (Battiste, 2000; Smith, 1999). In addition, I want to engage in a research process that contributes to decolonization within Aboriginal populations as there has been so much colonization via the vast amount of detached, primarily quantitative (qualitative research can be colonizing as well) research done. This continues to subjugate original people; Battiste (2000) discusses that colonizing research describes, objectifies and measures the "other".

In addition, this scientific distance in much of the historical and present day research with indigenous populations has and continues to keep the researched as other, savage, and crude. This encourages comparisons to be made amongst 'civilized' and 'uncivilized' peoples using a

scientific, western view of knowledge (Smith, 1999). Ultimately, this process continues to colonize Aboriginal people by appropriating culture, knowledge, experiences, and people.

This study is not interested in substance use as a blaming device. It is addressed in the literature review as it relates to colonization and may be addressed in this study in the context of spiritual learnings, overcoming addiction and locating personal strength. The study is not concerned with how the participants contracted the virus nor is it interested in perpetuating the stereotypes of Aboriginal women with HIV and AIDS. It is not a contribution to the notion that they deserved to contract HIV as a result of their behavior. Instead, this work is intended to highlight the strength, resiliency and observations of the women regarding their personal resources and the community resources that may or may not exist to serve their needs. In addition, this study seeks to inform the social work profession regarding work with Aboriginal women with HIV and AIDS. Recommendations for decolonization processes and practices will also be included with particular emphasis on Smith's (1999) and Battiste's (2000) processes of decolonization. There are a few newer sources for decolonizing processes with Aboriginal persons including working with Aboriginal peoples around identifying community strengths (Broad, Boyer & Chataway, 2006) and decolonizing strategies that are specific to educational curriculum representing Aboriginal peoples' experiences (MacDonald & MacDonald, 2007). I chose to have Smith's (1999) and Battiste's (2000) processes of decolonization central to this project for important reasons. One, both of the authors include specific processes that are relatively easy to explain and understand and which involve moving through different phases of decolonization. In addition, both authors' books include decolonizing processes that are specific to research and both authors are women who identify as indigenous or Aboriginal (Battiste, 2000; Smith, 1999). Battiste is also an Aboriginal Canadian woman who was the first Aboriginal woman to receive a doctorate degree. Another important reason for selecting Battiste's work for

this project was that she has continued to work in Canadian educational institutions stressing the role that education has in the decolonization process for Aboriginal peoples.

HIV and AIDS

The Public Health Alliance of Canada describes HIV as "a virus that attacks the immune system, resulting in a chronic, progressive illness that leaves people vulnerable to opportunistic infections and cancers" (2011, p.1). Once a person's body is no longer able to fight infections the disease becomes known as AIDS (acquired immunodeficiency syndrome) (2011). Other complications from HIV and AIDS include physical symptoms that may initially include fever, swollen lymph nodes, rashes, sore throat, and headaches (Mayo Clinic, 2011). In time these symptoms progress to chronic fatigue, severe fever, severe sweating, persistent diarrhea, dramatic weight loss, constant nausea, shortness of breath, lesions and severe chills (2011). It is important to understand how social workers and all helping professionals can contribute to increasing the quality of life for Aboriginal women living with HIV and AIDS by listening to the participants' experiences. To do this it is crucial that we understand the complications associated with living with HIV and AIDS and how these complications may be exacerbated by barriers that the women participants face in their day to day lives.

Context: Colonization and HIV/AIDS

In Canada one of the legacies of colonization is the disproportionate representation of Aboriginal persons who are infected with HIV and AIDS. Health Canada's website acknowledges that the high percentage of Aboriginal persons infected with HIV is partially attributable to the process of colonization (2005). Biological invasion, along with cultural, military and economic invasion combined with overcrowding, poverty and malnutrition to contribute to the eradication of first peoples (Lux, 2001; Mussel, 2006). Since Europeans first came to North America several hundreds of years ago, Aboriginal people have been

affected/infected by many new diseases. These diseases including small pox, cholera, bubonic plague, measles, and influenza, nearly obliterated Aboriginal people from North America. After only twenty years of European occupation (approximately 1600 AD), only one tenth of the Aboriginal population remained alive. It is estimated that as many as 90 million Aboriginal people died during this time period (CAAN, 2005; Mussel, 2006). Not only did Aboriginal people contract these new diseases very easily, they also died from them very quickly not unlike HIV today. Aboriginal people in British Columbia are twice as likely to contract HIV as non-Aboriginal people; once they have contracted the virus, First Nations people tend to seroconvert to AIDS and then die much more quickly than non-Aboriginal people (Public Health Alliance of Canada, 2007). This process for Aboriginal people can be very short often lasting less than two to three years (Clarke, 2003). The average seroconversion rate for all Canadians from initial infection of HIV to diagnosis of AIDS is over ten years without anti-retro viral treatment (PHAC, 2011).

Traditionally, when a member of an Aboriginal community is very sick, the Elders of the community gather around this person's bedside to offer the sick person their spiritual strength. This continued to happen during times of disease which resulted in the sickness and death of the leaders of Aboriginal communities at a time when wisdom, strategy and leadership were needed the most (Red Road, 2005).

Another factor in the legacy of colonization that contributes to the growing number of Aboriginal people contracting HIV is the over representation of Aboriginal people in Canadian prisons where intravenous drug use is common and continues to be the highest risk activity for contracting the virus (Health Canada, 2011). In Canada, 18 per cent of federal inmates are Aboriginal yet they only represent 3.8 per cent of the Canadian population (Public Health Alliance of Canada, 2011). Women identifying as Aboriginal represent over 33 per cent of

females incarcerated in federal institutions in Canada and this number has continued to increase over the past decade (Correctional Service of Canada, 2011). Incarceration rates increase to as high as 40 per cent Aboriginal inmates in provincial or federal jails in some provinces (Correctional Service of Canada, 2005). In addition to high rates of incarceration, poverty and substance use are also colossal multifaceted social problems that result from colonization, Indian reservations, exploitation, and residential schooling (Bucharski et al., 2006; Healing Our Spirit, 2005).

In order to understand the relationship between colonization and high rates of HIV infections within Aboriginal populations, we must understand the relationship between substance use and HIV infection. Estimates in British Columbia are that over 60 per cent of Aboriginal people infected with HIV have contracted the virus via intravenous drug use (CAAN, 2005). For Aboriginal women 64.6 per cent report contracting the virus by intravenous drug use and 32.8 per cent report contracting the virus via heterosexual contact (Public Health Agency of Canada, 2011). Research by McCall (2009) and Bucharski (2006) underscores the role of IV drug use and high-risk lifestyle as contributors. In addition to intravenous drug use, cocaine and alcohol use are also high-risk behaviours for contracting HIV as judgment becomes impaired with the use of these substances.

In 2004, [information on] the Red Road website (accessed 2005) noted that 80 per cent of Aboriginal injection drug users in the Vancouver area were being displaced and regularly returning to their home communities. As a direct result, the members of the home community were being placed at risk for HIV infection via sexual contact and/or intravenous drug use. This warning accurately predicted a future wave of high infection rates in northern and rural Aboriginal communities. According to Northern Health (NH), the Ministry of Health's Authority for Northern B.C., in their most recent HIV/AIDS report, the overall rate of new cases is above

that of the provincial average (2010). In 2009, the rate was 9.5 newly identified cases per 100,000 people, as opposed to the provincial average 7.5 (November, 2010). Again according to the NH report (November, 2010), intravenous drug users are still at highest risk and approximately 26 per cent of individuals who are HIV positive are unaware of their status. In terms of rates and numbers, the Northwest and Northern Interior regions within NH are now close to equal, though the Northern Interior has historically had higher numbers. Over half of the new cases in the Northwest are showing up among Aboriginal people, primarily men. It is also interesting to note that since 2007, there have been fewer Aboriginal females than non-Aboriginal females testing positive for HIV (November, 2010). Anecdotally, professionals working in communities tend to think that this is due to lack of testing, rather than fewer cases contracted. Similar data has also been reported in British Columbia by Bucharski et al. (2006) and McCall et al. (2009).

The imposition of European notions, values and beliefs onto Aboriginal cultures, which occurred in the process of cultural assimilation and residential schooling, resulted in the "dispossession of First Nations rights" (Ship & Norton, 2000, p. 70). The pain associated with this cultural dislocation is often masked or numbed with the use of substances (McCormick, 2000). Duran and Duran state that the disconnection of Aboriginal peoples from their culture was a "deliberate strategy utilized by various churches and the government of Canada in an attempt to assimilate Aboriginal people into Euro-Western culture" (1995, p. 27). For many Aboriginal people, the use of substances has been a way to deal with the hopelessness and powerlessness that has arisen due to the devastation of traditional cultural values. A number of authors have demonstrated this link between cultural breakdown and high levels of substance use (Duran & Duran, 1995; McCormick, 2000; York, 1990). Discussions surrounding colonization often focus on the process of colonization as a "past" historical context but, it is imperative that we continue

to recognize the policies and structures of HIV and AIDS organizations that continue to oppress, and discriminate against Aboriginal people.

Non-Aboriginal HIV/AIDS Networks

Networks included in this category are organizations that are major funding agencies, political advocates and policy makers regarding Aboriginal people's health. Health Canada, Pacific AIDS Network and Indian and Northern Affairs Canada are included. The Pacific AIDS Network (PAN) represents a network of HIV and AIDS organizations across British Columbia. Although Health Canada recognizes that Aboriginal people are twice as likely to become infected with HIV as non-Aboriginal people, in 2004, PAN did not have a specific strategy to address Aboriginal people and HIV and AIDS (Health Canada, 2005; PAN, 2005). Anecdotally, upon contacting PAN for information regarding strategies for addressing the high rate of infection within Aboriginal populations in British Columbia, I was directed to the Red Road and Healing Our Spirit, which are Aboriginal HIV and AIDS organizations in British Columbia. While it is encouraging that PAN was able to offer suggestions for accessing Aboriginal HIV and AIDS information, PAN is a network that is designed to provide service, advocacy, support and funding for all HIV and AIDS organizations across the province. It is crucial that they pay attention to the Aboriginal HIV and AIDS pandemic that is occurring and provide this information and support to the public. PAN is now engaging with a number of community stakeholders, including NH, in the Seek and Treat for Optimal Prevention (STOP) HIV Community Engagement Working Group (CEWG), which commenced in November of 2010.

STOP-HIV was piloted in Vancouver and Prince George, British Columbia. The fact that the program was piloted in these two areas indicated that both these areas were communities in which persons were testing positive at higher rates than other areas in the province. The advantage of the program is that test results are available within minutes; however this initiates a

need to have skilled HIV and AIDS counselors available at the time of testing. The CEWG reports to the STOP-HIV Leadership Committee. The CEWG is intended to advocate for community ideas and concerns to be included in the planning and decision-making processes, so that the diverse values and needs of the communities being served are taken into account. At this time, there is approval for the STOP HIV program to be branched out into Aboriginal communities in the North and there is the hope that this will happen sometime in 2011.

In much the same way, the department of Indian and Northern Affairs Canada (INAC) (even the name reeks of deeply entrenched colonialist values and beliefs) does not include any strategies, policies, statistics or even mention of Aboriginal people and HIV and AIDS in 2005. By 2011, this information was included on the Public Health Agency of Canada's website in relation to the department of Indian and Northern Affairs. On its own website, INAC describes the extent to which First Nations people live below the health and social standards of Canadians as a whole:

> They frequently live in conditions of poverty, unemployment and inadequate housing. They often have little control over the direction of their own lives and communities. Efforts to improve the determinants of health and the self-determination of First Nations people will significantly improve their lives overall and, specifically, in terms of communicable diseases, drug use and HIV/AIDS (February 25, 2011).

The message that these two organizations send via these interactions and policies is that Aboriginal organizations need to deal with Aboriginal clients. These policies and practices continue to keep Aboriginal issues on the periphery. This behaviour continues to support the colonizing practices and policies that have been occurring for hundreds of years (Battiste, 2000).

Another way that Aboriginal issues are kept on the periphery is through mainstream organizations' tendency to under/not value structures, and organizations that have values, practices and beliefs that are other than those structured by Western paradigms (Battiste, 2000).

It is not uncommon for non-Aboriginal organizations to pressure their Aboriginal counterparts to conform to Western organizational structures and theories (Smith, 1999). Smith (1999) and Battiste (2000) also discuss the tendency of mainstream organizations to focus on the struggles within Aboriginal organizations and thus devalue their existence, work and worth. The struggles described may include difficulties with collaborative leadership across organizations, mismanagement of funds, and a lack of unified vision within organizations (Smith, 1999). Both Smith (1999) and Battiste (2000) recommend that Aboriginal organizations also need to engage in the same processes of decolonization as Aboriginal individuals and communities, by mourning the past, dreaming what is possible and committing to specific action to move forward.

In my experience, these discrepancies are evident in the HIV and AIDS community in British Columbia as there have been differences in vision and philosophy between Aboriginal and non-Aboriginal HIV and AIDS organizations that have resulted in exclusive policies and practices on both sides. Over time, there continues to be an improvement in working relationships between Aboriginal and non-Aboriginal organizations through the efforts of individuals who see the benefits of a collaborative approach to health care.

During the last decade I have attended a number of Provincial HIV and AIDS conferences and during this time I have noticed an improvement in relationships between PAN, the Red Road and Healing Our Spirit. These changes have come about as a result of changes in leadership and this leadership talking about the need to focus on the issue, which is that Aboriginal people are the fastest growing risk group in the province. Smith (1999) advises that while it is crucial for non-Aboriginal organizations to include Aboriginal voice and vision, there is the need to ensure that Aboriginal representation is not token representation.

The apparent exception to this tendency within non-Aboriginal HIV/AIDS organizations in Canada is Health Canada. Health Canada actively funds research projects, makes joint (inclusive

practices) recommendations and funds and participates in initiatives that address the health and well-being of Aboriginal peoples in Canada (Health Canada, 2005). Health Canada also funded the Royal Commission on Aboriginal People in Canada and within this document there are a multitude of recommendations regarding moving society forward from colonization including the establishment of an Aboriginal International University; providing compensation for residential school survivors and their families; supporting healing and self-governance for Aboriginal peoples and stressing the importance of the need for Aboriginal people to have autonomy of culture within their communities and society at large (2005).

In addition to this, the Royal Commission on Aboriginal People also talks about the discrimination and racism that Aboriginal people face in attempting to access health care service organizations. In 2005 the Royal Commission stressed that the exclusive, racist and discriminatory policies of health organizations must be re-vamped to be inclusive and culturally appropriate to Aboriginal people. All of these recommendations are consistent with both Battiste's (2000) and Smith's (1999) theories regarding the process of decolonization.

The Royal Commission on Aboriginal People is a vast document outlining sweeping changes that are needed within Canadian governmental organizations in order for all members within society to engage in the process of decolonization. One of the concerns regarding these recommendations is that they are being made to the Canadian government, which is grounded in Western theories and ideologies. This is a concern because there is a tendency for non-Aboriginal organizations to believe that it is Aboriginal peoples' sole responsibility to heal their communities from the atrocities of colonization (Lynes, 2002).

Aboriginal HIV and AIDS Networks

Networks included in this category are Aboriginal organizations that are funding agencies, political advocacy organizations and strategy/policy makers regarding Aboriginal people

infected with HIV and AIDS in British Columbia. Positive Living North (PLN), Healing Our Spirit and the Red Road are included. In stark contrast to non-Aboriginal HIV and AIDS networks, Aboriginal HIV and AIDS networks' mission statements include reference to the importance of culture in the healing and de-colonization process (Healing Our Spirit, 2005; Positive Living North, 2005; Red Road, 2005). All three of the agencies referenced also stress the importance of healing *all* peoples within society in order to stop the HIV and AIDS pandemic that is decimating Aboriginal peoples and communities in general across the province. The Red Road HIV and AIDS Network demonstrates their inclusive vision by stating right on their home page "it is the belief of the members of the Red Road HIV/AIDS Network that all peoples are affected by HIV/AIDS" and that their membership, policies, resources and practices extend to non-Aboriginal HIV and AIDS service organizations (Red Road, 2005).

This collaborative approach to HIV and AIDS within Aboriginal communities has not always been this supportive and inclusive. For years Aboriginal leaders and communities have dismissed HIV and AIDS as a gay male disease and with high levels of homophobia within Aboriginal communities it "has been a struggle to convince some Aboriginal leaders that HIV/AIDS is simply another deadly disease" (CAAN, 2005). Again, education, cultural practices and healing have proven to be effective tools of decolonization in this matter as prior to European contact most Aboriginal communities in Canada acknowledged and respected two-spirited persons within their communities (Healing Our Spirit, 2005). It is clear through this culturally appropriate education and attention to policies and practices that incorporate spirituality, "Aboriginal leaders, community health workers and policy makers are beginning to understand that HIV/AIDS affects all of us" (CAAN, 2005).

PLN, Central Interior Native Health Society (CINHS) and Healing Our Spirit have initiated efforts to address HIV and AIDS within rural and remote Aboriginal communities in

northern British Columbia. It has been vitally important to authentically incorporate spiritual and cultural practices into learning events within Aboriginal communities. Another area in the process of decolonization that continues to be adhered to within Aboriginal HIV and AIDS organizations is the need to conduct culturally appropriate research with Aboriginal people that is conducted by Aboriginal people (Smith, 1999). A good example of this type of research in Prince George is The Cedar Project. The Cedar Project is a "community based research initiative that addresses hepatitis C and HIV vulnerabilities among young Aboriginal people who use illicit drugs in three cities in British Columbia, Canada" (The Cedar Project, 2011, p.1). Other examples of local research done for and by Aboriginal peoples include *In From the Margins* (CINHS, 2005) and *Barriers to Treatment: Aboriginal People and HIV/AIDS* (Positive Living North, 2005). The Northern BC Aboriginal Task Force on HIV/AIDS, established by the chiefs from all of the 60 Northern Nations and chaired by Emma Plamanteir, is an active participant in facilitating change. PLN, CINHS, Carrier Sekani Family Services, PHAC, community representatives and people living with HIV are all working toward support, prevention, education and management of the pandemic in a variety of ways through the task force.

Policies of Decolonization

The traumas, losses and grief experienced as a result of colonization continue to be experienced by Aboriginal people via the policies and practices of mainstream organizations (Royal Commission, 2005). My personal experience with this includes starting work in a non-profit agency in the Nechako Lakes District in northern British Columbia. The organization's clients are ethnically diverse with over 55 per cent of the clients identifying as Aboriginal. Despite this, there were no policies or practices in place that supported collaboration and consultation with the surrounding Aboriginal communities. In addition, there were no Aboriginal Board members and only one Aboriginal staff member. The question becomes about how

networks, organizations, communities and society stop this process of colonization that continues to afflict the most vulnerable members of society. It will be indicative of progress when no one is excluded from this process.

Mills and Simmons (1999) discuss the need for all organizational structures to look at how imperialism has impacted society's views and values of employees and clients according to Western standards. The Royal Commission on Aboriginal People continues with this theme by recommending that the Canadian government pay particular attention to appointing and hiring mass numbers of Aboriginal people to be involved in research into the lasting impacts of colonialism and how organizational structures within Canada continue to perpetuate colonization (2005). The Royal Commission highlights the importance of acknowledging the lasting impacts of residential school policies and practices by "respecting all Aboriginal peoples, with particular attention to the nature and extent of effects on subsequent generations of individuals and families, and on communities and Aboriginal societies" (2005, Appendix A, 1.10.1).

Battiste (2000) talks about five distinct phases in the process of decolonization including: rediscovery and recovery, mourning, dreaming, commitment and action. These phases are often occurring at the same time within individuals, organizations, communities, and society. The rediscovery and recovery phase includes a process of discovering the facts about colonization, and then starting the process of recovering one's history and culture (Battiste, 2000). This process has been occurring for Aboriginal people in Canada for decades but, Battiste warns of the tendency of Aboriginal people to continue to look at their traditional cultures from the perspective of the colonizer (2000). Exploitation of Aboriginal cultures is still occurring in the rediscovery and recovery phase of decolonization (2000). Healing Our Spirit (2005), CAAN (2005), and Positive Living North (2005) try to ensure that the liminal space between

colonization and decolonization is more safely navigated by learning from and incorporating Aboriginal elders into the process of change.

During the second phase of decolonization Battiste (2000) describes the process of mourning as often including feelings of anger, victimization and a need to "lament their victimization" (p. 154). Peoples' experiences of anger during this phase are often directed toward educational systems for misrepresenting the history and experiences of Aboriginal people (Battiste, 2000).

The third phase of decolonization as described by Battiste (2000) involves dreaming. During this phase it is important for Aboriginal people to explore their own culture and to ensure that the process of "decolonization is more than simply placing Indigenous or previously colonized people into the positions held by colonizers" (Battiste, 2000, p. 155). In the North, it is becoming more common for organizations to engage in consultation with Aboriginal elders from surrounding communities and community forums to include the voices of all community members. The internal process of re-vamping organizational policies and procedures to reflect Aboriginal cultures and traditions is ongoing and a project that will likely remain fluid for years to come. My experience as the Executive Director of a northern, rural and remote non-profit community services organization is consistent with this trend. Maintaining our international accreditation standards means that we are required to have employees and governors that are representative of the communities that we serve. This means our policies and resulting practices reflect the need to recruit and retain Aboriginal employees and Board members. In addition, we are required to provide cultural competency training for each and every employee on an annual basis which includes consulting and contracting local community elders to provide this training.

The fourth phase of decolonization is characterized by commitment to a unified vision and/or goals within the Aboriginal community. This phase includes political formation including self-determination and educational reforms which are also a part of the third phase of decolonization

(Battiste, 2000). It is also important to remember that during the phases of decolonization we must keep in mind our allies and support their movement through the process as well. As a white skinned woman with many places of privilege in Western society, I struggled for years about my role in the process of decolonization. It was difficult to integrate having a voice in the process of decolonization with the feeling that I did not have the right to speak up as a white skinned woman. In time, I have realized that not only do I have a right to speak up about my experiences and feelings around colonization but, I have a responsibility to speak up about and engage in decolonization.

The fifth phase of decolonization includes the action that is to be taken as a result of the dreaming and commitment phases (Battiste, 2000). There are many forms that action can take during this phase including passive resistance, warfare, political lobbying and media relations (2000). The fifth phase is only one of the phases of decolonization, and Battiste advises that colonized people may not move through the grieving process in a linear fashion (2000).

Recommendations

CAAN recommends that the following strategies must be put into place in order to support the process of decolonization:

- More education and better information among Aboriginal people in Canada is needed to guide prevention and control strategies.
- More on-reserve, northern Inuit and Métis programming and treatment must occur. The barriers between leadership and rival political groups must be broken down, and issues of homophobia must be addressed on-reserve, northern and remote rural communities.
- More Aboriginal programming and education in prisons and institutions must be provided.
- Communities must take an active role in the education of their children and members about the dangers of unprotected sex and other risk associated behaviours (2005).

In addition to this, the Royal Commission on Aboriginal People has recommended that the Canadian government not only establish an International Aboriginal University but that the Canadian government also:

> commit[s] to publication of a general history of Aboriginal peoples of Canada in a series of volumes reflecting the diversity of nations, to be completed within 20 years; allocate funding to the Social Sciences and Humanities Research Council to convene a board, with a majority of Aboriginal people, interests and expertise, to plan and guide the Aboriginal History Project; and pursue partnerships with provincial and territorial governments, educational authorities, Aboriginal nations and communities, oral historians and elders, Aboriginal and non-Aboriginal scholars and educational and research institutions, private donors and publishers to ensure broad support for and wide dissemination of the series (2005, Appendix A, 1.7.1).

Locally, there have been a number of research projects in the Prince George health community that looked at the barriers to health for Aboriginal people with HIV/AIDS including the previously mentioned *In From the Margins,* and *Barriers to Treatment: Aboriginal People and HIV/AIDS* (CINHS, 2005; Positive Living North, 2005). These research projects not only required at least one of the principal researchers to be Aboriginal, requirements also included that Aboriginal leaders in the surrounding communities must be included via steering committees, advisory councils, focus groups and by recounting their experiences. While these recommendations and projects supported the process of decolonization, there is a big piece of the puzzle that continues to be absent. Despite the sweeping recommendations made by the Royal Commission on Aboriginal People, there has yet to be any action taken towards these initiatives by the institutions and governments within Canada that the commission was addressing (CAAN, 2005). Until these practices and policies start to be adopted by mainstream organizations and societies within Canada, Aboriginal people will continue to experience barriers to healthcare, poverty, discrimination, and racism which will exacerbate the already perilous HIV and AIDS pandemic for Aboriginal people. The province of British Columbia now has an online cultural

competency course, which all health care providers are required to take. Dr. Evan Adams reported at the Men's and Women's Health conference, sponsored by NH and CSFS, that only 6 per cent of health care providers have completed the course to date.

Summary

Aboriginal people in Canada continue to be infected with HIV at alarming rates. Not only is this a result of historical policies of colonization and imperialism, current policies and practices of colonization within mainstream organizations continue to keep Aboriginal people on the periphery and thus continue to deny them equality of access to health (CAAN, 2005; Northern Health Report, 2010). It is obvious that while there are a number of organizations involved in the process of decolonization, many of the current policies and practices surrounding Aboriginal people with HIV and AIDS or at risk for contracting HIV and AIDS are not working.

The economic and social inequalities for Aboriginal people are a result of the processes of colonization. In order to address the HIV and AIDS pandemic that is occurring within Aboriginal communities, the process of de-colonization must not only be adopted within Aboriginal organizations, but within mainstream organizations as well. As noted above, this can only be accomplished through integrating culturally and spiritually appropriate educational systems, supporting and funding Aboriginal conducted research, design and implementation of policies and practices acknowledging the process of colonization and recommendations for all organizations to participate in the process of decolonization (Battiste, 2000; MacDonald & MacDonald, 2007). Although, it doesn't appear that current organizational policies and practices in some areas are dealing with the HIV and AIDS pandemic, Battitste suggests being careful not to move through the process of decolonization too quickly (2000). During the process of decolonization particular attention must be paid when changing society as there is the chance that

we will simply become entrenched deeper into the exact systems, societal values and controls maintained by the colonizer (Battiste, 2000).

Location of Author

I come to this work not only as a social worker working with HIV+ Aboriginal women but, also as a Métis woman with a passion for all my relations. Growing up in a white skinned home that celebrated our genealogical connection to Scotland, it wasn't until I was an adult that I started exploring my mother's familial background and the connection we have to our Aboriginal ancestors. Initially, understanding the silence around the Aboriginal blood in the family involved much individual work, deconstruction of shame and abandonment and the reconciliation with a racist past through reading and gaining and understanding of my experiences (Graveline, 1998; Maracle, 1996; Reinharz, 1992). Over the years I have started to focus externally on the racism and colonization of our people. I have been particularly disturbed by studies done 'to' women with HIV, the lack of research done with, for and by Aboriginal women with HIV and the emphasis on blaming HIV positive Aboriginal women for contracting the virus.

My understanding of responsibility (colonization) for the HIV pandemic that is infecting and affecting Aboriginal women at an alarming rate is much different than the locus of responsibility that is inherent in the literature/research that I have read (Herlitz & Ramstedt, 2005; Hoffman-Goetz, Friedman & Clarke, 2005; Ryan, 2000). I am exhausted and angered by the perpetuation of blame that is attached to the discourses around Aboriginal women who are HIV+ (Artz, Macaluso, Kelaghan, Austin, Fleenor, Robey, Hook III, & Brill, 2005; Kalichman, Rompa & Cage, 2005) and the need for Aboriginal women's voices to actually be heard is long past due. While much of the research in this study will focus on Aboriginal women's strengths, it is my desire and responsibility to not only demonstrates the relationship between colonialism and

the contraction of HIV for Aboriginal women but, also to include recommendations for the social work profession regarding supporting and helping to facilitate the process of decolonization.

CHAPTER TWO: CREATIVE TRANSFORMATION

It is often difficult for marginalized groups and individuals to claim voices that are not a product of dominant, Eurocentric, white patriarchal societies but to also have these voices heard in the context of minority experience. This struggle to find and/or create the space in claiming one's voice via creativity is not a new struggle for indigenous people. Though creativity may take a number of forms, such as drumming, dancing, or carving, over time this struggle has increasingly become a struggle of representation:

> All colonized and subjugated people who, by way of resistance, create an oppositional subculture within the framework of domination recognize that the field of representation (how we see ourselves, how others see us) is an ongoing struggle (hooks, 1995, p.57).

Nona West and Joyce Stalker quote Edward Said (1993), who noted that imperialism was the "practice and theory of a dominant metropolitan centre ruling over a distant territory" (in Clover & Stalker, 2007, p.125). It is arguably true that the dominant hegemony of European colonizers taught First Peoples on all continents to see themselves as "exiles from the marginal to the real world" (in Clover & Stalker, 2007, p.125). It is in this context that I will discuss the creative process as part of the struggle to process my own identity and the material presented to me by the participants of this project. It is fundamentally important for me, as a Métis woman, to be able to define the key elements of my familial, national heritage/identity, not only relative to my self in a personal way, but also relative to other Aboriginal women who may or may not share common experience with me aside from the ravages of colonization on personal identity.

Regarding the role of creativity in facilitating identity recovery, it is important to note that this process exists as a double-edged sword. The creative process, especially for First Nations people working in traditional mediums, can help to learn about, preserve, and support our own

culture. Unfortunately, it is also possible to support the dominant culture and, potentially, colonize other cultures (Hood, 2001; Moore, 1994 in Clover & Stalker, 2007). Despite the risks inherent in returning to traditional forms of working, I realize, in conjunction with West and Stalker (in Clover & Stalker, 2007) that the 'more positive learning agenda' consists of a clearer understanding of the issues of personal identity, of the wider culture, decolonization, and multiculturalism as per my Métis heritage. This process is helping me to deconstruct old versions of self, to understand the impact of colonization on my personal and cultural identity, and to un-learn the biases and prejudices that were inherent in my upbringing.

Discovering and recovering creative voices is an ongoing process over an individual's life course, and, in the context of decolonization, in the ongoing recovery of cultural identity. Cameron (1998) discusses the reality that we each have a unique voice and that we need to not only discover these creative voices but to re-discover these creative voices in an ongoing way. In the context of colonization and appropriation of indigenous peoples' culture, creativity and identity, it is crucial that creative voices are not a perpetuation of dominant value systems. Through legitimized stereotypical representation of indigenous peoples, there is a perpetuation and validation of colonization (Battiste, 2000). hooks (1995) speaks of the need to inform a new critical culture in which minority creativity (art, etc.) can be discussed "in ways that confront not only the legacy of subjugation and radical traditions of resistance, [but also] the newly invented self, the decolonized subject" (p.93). Without this critique of indigenous culture, art continues to be created by indigenous people for the dominant culture to purchase. This destruction, confinement of artistic freedom, and subsequent loss of creative voice again leads to the perpetuation of colonization (hooks, 1995, p. 132).

Part of the process of decolonization for indigenous peoples includes the process of reclaiming their own traditions of creativity (Battiste, 2000; Smith, 1999). This is crucial in

relation to the history of colonization and the present and future of decolonization with indigenous peoples as art and creativity has been an integral part of the continued process of colonization:

> if one could make a people lose touch with their capacity to create, lose sight of their will and their power to make art, then the work of subjugation, of colonization is complete. Such work can be undone only by acts of concrete reclamation (hooks, 1995, p. xv).

This reclamation of indigenous voice, and vision through storytelling and creativity, as noted in hooks' quote above, clearly needs to be a part of the work that is done by helping professionals and support of this reclamation through creativity needs to be included in the work done with colonized peoples (Battiste, 2000; Smith, 1999; Turner, 1999). This is exemplified by a number of local initiatives; for example, *Voices and Visions: Creativity as a transformative process in a northern context* (Harding, 2010). This project invited marginalized women, primarily of First Nations descent, to tell their stories and to make their own contributions to theorizing in regards to homelessness and marginalization. She writes:

> Phenomenological art/visual ethnography counters traditional definitions of art. It appreciates the power of creative process and pays homage to the origins of the feminist art movement. Feminist art and art criticism are grounded in political activism, social analysis and self-knowledge thereby underscoring the validity of voices, which may have been marginalized due to race, class, gender and sexuality (2010, p. 6).

It is understood that visual art itself is a created perspective (Leavy, 2009), and it is important that each individual be supported and encouraged in their right to develop their individual perspective on the world. In other words:

> To see meaning as conjectural is to suggest that what are normally described as —objective truths are better understood as events or moments in which we are looking at or experiencing a unique

> coming together of particular forces, of relations and their history, and of space-time frames—and that all of these elements can vary according to how we adjust our lens (Merino, 1996 in Harding, 2010, p. 11).

My own creative processing of identity issues, and personal and professional commitments, along with the privilege of offering a forum for the interviews, is part of creating and providing opportunities for new 'created perspectives'. These new perspectives provide opportunities for improvement to services, understanding of barriers and increased empathy for the realities of individuals who are part of non-dominant cultures here in the North.

Traditionally, images have been and are being used to create and reinforce dominant hegemonic values; additionally, it needs to be noted that visual languages are also spaces of individual or cultural resistance. Leavy notes that visual art can effectively 'challenge, dislodge and transform outdated beliefs' (2009, p. 216). My experience is that the creative processes of carving, photography and creative writing have been effective modes of inquiry and resistance for me as a Métis woman. As noted by Collier and Collier (1986; 1996 in Leavy), I am using my creative processing as a non-verbal connection between my personal growth and exploration and the information/insights offered to me by the women who participated in the study. This work is for me, a familiarization of my emergent understandings and a process of stepping outside of hegemonic processes (Leavy, 2009).

CHAPTER THREE: LITERATURE REVIEW

Contemporary Ethnography and Cultural Studies

Denzin's (2001) book *Interpretive Interactionism* (2nd ed.) includes a description of interpretive interactionism referring to the "attempt to make the problematic lived experiences of ordinary people available to the reader; the interactionist interprets these worlds, their meanings and their representations" (p. xi). Throughout the book Denzin describes methodological approaches including performance texts, autoethnography, poetry, fiction, open-ended and creative interviewing, document analysis, semiotics, life history, life story, personal experience, self-story construction, participant observation and thick description in which the interpretations are made visible (2001). Denzin focuses much of his work on the importance of making interpretive research available to readers, how to do this and he devotes several chapters to thick description including criteria, methods and uses of thick description (2001, Chapters 5, 6, 7, conclusion). In reading and interpreting Denzin's book one of the main themes to emerge is that "in the world of human experience there is only interpretation" (p. xii) and these interpretations are works in progress constantly being interpreted by readers, participants and audiences (2001).

This book informs my thesis work by providing a framework for interpretive studies. Denzin has been and will continue to be a significant informant to the research. Denzin's description of open-ended interviewing fits how I want to work with and for Aboriginal people. It also appears to be an excellent format for engaging in discussions with Aboriginal people due to history of oral tradition within the culture.

Saukko (2003), a former student of Denzin's, expanded on Denzin's work by outlining the importance of the interaction between intimate experiences of the self and institutional discourses within the global, political and social context. Saukko outlines a handbook of combining cultural studies methodologies. This handbook has been informing my thoughts on

how to engage in research that is congruent with finding meaning, inclusive of participant voices and which includes a post-structuralist discourse. In chapter one of this book Saukko discusses combining methodologies with a particular emphasis on the idea of prisms and the "social construction of reality" which "conveys many realities" within the prism paradigm (p. 25). The diagram found later in this proposal is a result of integrating Saukko's ideas of combining methodologies with my own. I also find that her attention to resistance, as informed by her earlier studies, fits well with my thesis topic as I want the strengths and places of resistance within the participants to be illuminated by their words and our interpretations of these words (2003).

Creative Process: Colonization and Decolonization

In her book, *art on my mind: visual politics,* bell hooks makes clear the connection between creativity and the reclamation of indigenous peoples' voices and visions of the future (1995). She also discusses the importance of finding or re-discovering a cultural critique that supports and validates the unique creativity of indigenous peoples. The reality is that historical and contemporary appropriation, in addition to the dominant culture's legitimization of certain indigenous artists, perpetuates colonization. This process is clearly outlined by hooks (1995). In addition, hooks makes the connection between the need to claim our voices through creating art for ourselves and not for the dominant culture as a way of working towards reclamation of cultural identity thus reclaiming the process of decolonization. The idea and action of offering a voice and connection to the knowledge within indigenous people that counteracts the appropriation of culture, creativity and indigenous identity that continues to be the reality within dominant societies, fits directly with my intentions.

In her book, *"Real" Indians and Others: Mixed blood urban native peoples and Indigenous nationhood* (2004), Lawrence talks about Aboriginal peoples' loss of identity via the process of

colonization and categorization as "aboriginal" or "non-aboriginal". This categorization is based on the dominant ideology's legal definition of what makes a person Aboriginal. Lawrence includes a gendered analysis of the removal of identity and how this has particularly affected off reserve Aboriginal women. She also discusses the particular loss of identity for urban Aboriginals; additionally, she addresses struggles for survival and regaining identity in a society that fails to recognize persons with 'mixed blood' as being Aboriginal. This book is refreshing, evocative and it contains numerous interviews with urban Aboriginals, as well as reviewing literature and governmental laws and policies that have been utilized to inform the identities of Aboriginal peoples for decades. This book informed my thesis in many ways; in particular, at the early stage in the process, it informed the struggles that I had around my own mixed blood identity and the roadblocks that I have internalized in proceeding with the project. The first hand accounts via the interviews with urban Aboriginal people of mixed blood have been particularly grounding for me as I feel that I am not alone in my struggles with identity.

Much debate exists in the world of academia regarding whether doing research without ensuring that the research is socially responsible and meaningful for the participants and researcher is ethical (Battiste, 2000; Denzin, 2001; Saukko, 2003; Sherman & Reid, 1994; Smith, 1999). In *Decolonizing Methodologies*, Smith discusses the role that research has and continues to play in the role of colonizing indigenous peoples. She clearly articulates the need for research to be done for and by indigenous researchers and that this work be done in adherence to the research ethics that indigenous populations value. These values are in opposition to the positivist paradigm that is valued by the dominant Western ideology and which dictates how, why and when research is done and disseminated. Smith's discussion around the role that research has played in colonization is crucial but, I find her attention to the processes of decolonization and the role that research plays in this process invaluable in formulating my own thoughts regarding

my personal involvement in this process. This occurs for me as a researcher, as a Métis woman, and as a social worker.

In the years spanning the writing of this project, there has been very little in the way of literature published in regards to Aboriginal women living with HIV in the North. There were however, two significant studies that are relevant to this work not only because they deal specifically with the topic, but also because the similarity of the results increases the validity of this research via the fact that the results are reproducible and generalizable to First Nations women living in BC, Canada and the United States. McCall, Browne, and Reimer-Kirkham (2009) suggest that the increasingly high rates of mortality and morbidity among Canadian Aboriginal women who are living with HIV and AIDS indicated that there is a necessity to address deficiencies in the delivery of supportive services and health care, and in addition, these needs have to be addressed according to the perceived needs of the individuals accessing the system.

The purpose of the qualitative study done by McCall et al. (2009) was to develop a better understanding of the barriers, challenges, and successes that First Nation's women experience when accessing health and related services. Similar to my own study, the findings were organized around themes reflected in qualitative interviews. These themes were 'fear of rejection when seeking services', 'finding strength in adversity', 'struggles with symptoms' and 'HIV as one of many competing problems' (McCall et. al., 2009). As in my study, the authors anticipated that the findings from the study will be used to inform decision making regarding the development and delivery of appropriate, responsive, and accessible policies and programs that will support Aboriginal women who are living with HIV and AIDS (McCall, Brown & Reimer-Kirkham, 2009).

In relation to the methodological approach to qualitative inquiry, this study is also relevant because it emphasizes the "constructed and contextual nature of human experience, while at the same time, allowing for shared realities" (Thorne in McCall et al., 2009, p. 1711). For the women in the study (McCall et. al. 2009), dealing directly with their HIV infection and the progression to AIDS was not often possible given the daily struggles for securing housing, some form of income, food, and support. The authors (2009) note that the four themes that emerged marked the "intersecting forces of discrimination, impoverishment, and the women's experience of violence, substance abuse, gender inequalities and social isolation" (p. 1777); that being said, they also highlight the importance of the women's self reported sense of resiliency in the face of adversity. This is of primary importance in order that First Nations women are not continually constructed as "victims without agency, and to deterministically bind them to a history that was never theirs to decide" (Adelson, in McCall, et. al., 2009, p. 1777).

Additionally, Bucharski, Reutter and Olgilvie (2006) put forward a qualitative, descriptive study intended to elicit Canadian Aboriginal women's perspective on culturally appropriate HIV counseling and testing. Though the seven interviews and single focus group did not occur in British Columbia, they did occur in a western Canadian city and the nuances add to what the women contributed to here in Prince George in my project. The fear of being judged by both the Aboriginal and non-Aboriginal communities and the need for sensitivity to the historical and current context of Aboriginal women's life experiences were pervasive themes throughout the findings.

Relevant Local Research Literature

Local Projects including *In From the Margins* and *Barriers to Treatment: Aboriginal People and HIV/AIDS* looked at ways that community based research could assist in developing strategies consistent with Primary Health Care that improved access to health services for

Aboriginal persons living with HIV. Both of these projects are relevant to this research with HIV positive Aboriginal women as all three projects are dealing with barriers to accessing appropriate resources for Aboriginal persons with HIV. The two initial projects focused more exclusively on access to health services within a Primary Health Care model and this project has one portion of the research addressing accessibility to helping professionals.

In Prince George, *Seek and Treat for Optimal Prevention of HIV/AIDS (STOP HIV/AIDS)* has been established by the BC Government as a pilot project commencing in February 2010 and lasting for four years. This program will expand access to HIV and AIDS medications among vulnerable and marginalized populations. It is projected that in Prince George, the project will improve and increase early detection, improve access to high quality care and treatment, and support the building of relationships and partnerships at the provincial and local levels (Northern Health Report, 2010). The STOP HIV and AIDS project has funding to expand into surrounding Aboriginal communities and this project will help inform potential barriers to access when this happens. For example, judgment and lack of anonymity have been discussed in many of the projects listed above and this theme emerges again in this project around accessing home community and urban resources.

In recent years Positive Living North has established a satellite office in Smithers, British Columbia in order to better serve clients living outside of the urban area. Members of PLN, those living with the disease and its impacts were helping and supporting each other. As one member said: "This disease stops with me. I am the front line of defense in the fight against HIV" (Robin, 2010).

The Positive Prevention Project arose from the staff observing members as capable and resourceful and the members themselves finding security in a solid community resource. As members are helped to stay healthy, they increase their capacity to educate others in ways that

may not be welcome from more official or clinical sources. For example, one individual in community believed that HIV/AIDS could spread through touching of food sources such as moose or salmon until corrected by members of the Frontline Warriors. The Frontline Warriors offer firm, educated and culturally relevant information (Northern Health Report, 2010).

The Aboriginal Task Force is composed of Aboriginal community leaders, elders, and youth, along with people who are living with HIV/AIDS. Additionally, it includes local, regional, provincial and federal government members, RCMP and health professionals along with representatives of agencies and health service providers who contribute to the efforts of the Task Force (Northern Health Report, 2010). A number of initiatives have taken place over the last year, such as a youth produced video titled *Our children, Our future: HIV in Aboriginal Communities*; additionally the Task Force sponsored a successful poster competition, the results of which will be made into a calendar. A Northwest Leadership Forum is in the planning stages, and face-to-face meetings are ongoing in order to facilitate culturally appropriate community education (Northern Health Report, 2010).

Summary

Clearly noted via the literature review, there are a number of local research projects and organizations that are making a positive difference in the lives of Aboriginal women with HIV and AIDS. These organizations including PLN, CINHS and the Native Friendship Centre embrace decolonizing methodologies in the work and planning that they do for community members. This is done through involving Aboriginal leaders in organizational planning, designing research projects and by including participant voices in organizational policy and process development. Performance ethnography uses the performances of everyday life to understand experience and to inform a method to practice. Cultural studies focuses on culture making institutions of society such as the organizations mentioned above and educational

institutions that inform professional behavior and practice within social work. Performance ethnography in this project will focus on the oral histories and stories of the women participants' everyday lives to inform decolonizing practices that are occurring and that need to happen in helping professional organizations in northern British Columbia.

CHAPTER FOUR: RESEARCH APPROACHES

As I wrote earlier, much debate exists in the world of academia regarding whether doing research without ensuring that the research is socially responsible and meaningful for the participants and researcher is ethical (Battiste, 2000; Denzin, 2001; Saukko, 2003; Sherman & Reid, 1994; Smith, 1999). One of the main principles in engaging in research as a social worker is to ensure that there is meaning and social change in, and as a result of, the study/research for both the participants and the researcher. Just as one cannot ethically engage in research that is not meaningful for the individuals and communities that one works with, one cannot engage in a piece of research, such as this thesis, without making sure that there is meaning in the work. It is with this in mind and soul that the first part of this chapter will attempt to frame the positivist paradigm's assumptions of a describable, predictable world that is external to the viewer and from which discoveries may be made and the impact, including perpetuation of colonization, of this in indigenous communities. Ethnographic methods including how this paradigm addresses the issue of objectivity through researcher physical, emotional and interpretive distance in method will be discussed with an emphasis on implications, including contributing to the process of decolonization, for this type of research within indigenous communities. Ethnography in this paper refers to the new school of ethnography including interpretive interactionism, and performance ethnography.

Positivist Research Paradigm

At the heart of the positivist paradigm is the belief that "something is real if it can be perceived" (Kaboub, 2002, p.22). Not only does positivism suggest that there is one truth but that this truth can be perceived via employing systematic scientific methods by all who research it and that this discovered 'truth' is universal. Heaton also discusses the notions of this single truth

or reality as being tangible, describable and fragment-able which further supports the positivist notion of a predictable world that is external to the observer (2004).

In positivist research/inquiry, the researcher is assumed to have no bias as in order to 'see' and describe the truth accurately one must have an objective view of what one is studying/observing/describing (Kaboub, 2002). In addition to this, the positivist paradigm asserts that what one is studying is often first studied within a closed system or environment. These experimental results are then taken from the "closed or experimental environment and applied in the empirical world" (Kaboub, 2002, p. 24). Descartes view is that determining reason is the best way to generate knowledge about reality noting that events are methodically ordered and yet they are interconnected (1998). Positivism is a very structured, ordered, objective paradigm that demands distance between the researcher and researched in order to discover the 'truth'. While this may be necessary in some circumstances (such as seeking a cure for HIV and AIDS), it is exactly these kinds of positivistic values and beliefs that have supported colonial practices in doing research with indigenous peoples.

Implications of Positivist Research with Indigenous Peoples

Battiste discusses why colonization has been so persistent among First Nations (2000); she continually emphasizes the role that positivist, scientific research has played in colonization. If we look at research with indigenous peoples, it is easy to see how hard science and the positivistic paradigm have contributed to the appropriation of culture, lands, voices and entire populations (Smith, 1999). With this dominant world view in the research, it is impossible for the researched to be described, objectified and measured free of deficiency.

In addition, this distance in research with indigenous populations has been and continues to be, maintained within the positivist paradigm by keeping the researched as other. This encourages comparisons to be made amongst 'civilized' and 'uncivilized' peoples using a

scientific, western view of knowledge (Smith, 1999). At the same time, it is difficult to do decolonizing research with indigenous populations as most research is funded by large institutions that are biased toward positivist approaches to knowledge accumulation.

I have written grant and funding proposals for over ten years and have found that the format, language and grammar required needs to support quantifiable outcomes. This is the same type of language that supports scientific provable knowledge and helps to ensure that grant proposals are funded. While quantifiable outcomes may have their place in some situations, this is not necessarily the language of the persons and communities that we are doing research with. If this is the reality that exists, the next logical question is 'how do researchers engage in research with indigenous populations that supports the process of decolonization?' It is important to note here that one of the ways that indigenous peoples' issues are kept on the periphery is through mainstream universities and institutions tendency not to value structures, languages, and organizations that have values, practices, beliefs that are outside the parameters of Western ideologies (Smith, 1999; Battiste, 2000). Appeasing research funders is but one example of the way that Western institutions exert pressure to have indigenous research organizations conform to Western language, theories and ideologies (Smith, 1999).

Ethnographic Research Paradigm

Ethnography is described by Denzin as "the study of lived experiences involving description and interpretation" (2001, p. 158). Very much in contrast to the positivist paradigm, contemporary ethnographic perspectives including works by Denzin (2001; 2002; 2003), Saukko (2003) and Grossberg (1999) state not only the necessity of understanding that there exists a dominant worldview with very strong ties to the principles of positivism, but, to also develop and utilize skills that support experiences, stories, and lives as told by those indigenous peoples who experience it. Blommaert discusses contemporary ethnography as a form of counter-hegemony in

that the discourses on race, gender, ability that are involved in contemporary ethnography are views that are less than mainstream, Western ideology (2005).

More and more, ethnography is utilizing skills such as interpretive interactionism, performance ethnography and cultural studies and relying less and less on "'the field of study' [as] it tends to obscure more than it illuminates" (Grossberg, 1999). Grossberg and Denzin (2002; 2003) are both very clear that this evolution of ethnography does not mean that researchers do not need to engage in field work; in fact state that this is still essential to ethnography but that the definition of field work has changed over time. Grossberg discusses the idea that contemporary ethnography needs to:

> open a space within which the complex nature of indigenous identity can begin to be explored as an important phenomenon in itself in which greater analytical emphasis is placed on the specifics of particular constructions of identity at particular times in particular places (1999, p.11).

This type of ethnographic research with indigenous peoples is desired, in part, because within the historical context of ethnographic research there is clear evidence that ethnographic research was a piece of the colonizing of numerous cultures (Denzin, 2001; Grossberg, 1999; Health Canada, 2005). Contemporary ethnography takes this further by not only wanting to avoid the mistakes of the past but to, participate in research with indigenous peoples that is meaningful, contextual, discursive, interactive and that also contributes to decolonization (Smith, 1999; Battiste, 2000). In addition to this, there is a commitment on the part of the researcher to engage in research methods that "question the epistemologies of Western science that are used to validate knowledge about indigenous peoples" and that is "characterized by the absence of the researcher's need to be in control" (Denzin, 2003, p. 6).

Implications of Ethnographic Research with Indigenous Peoples

Smith discusses the importance of adhering to the principles of ethical research in working with indigenous peoples and many of these ethical principles are supported via contemporary ethnographic principles as described above (1999). Smith and Battiste (2000) also discuss the need for research discourses that name colonization and the Western domination of 'valid' language. I volunteered as a Board member for CINHS from September 2001 until June 2005 and during that time research policies were developed that support decolonization by involving Aboriginal elders and community members in any research that may take place within their communities. This is congruent with the ethnographic belief in the poly-vocality in research design and practice.

The debate regarding race relations and indigenous peoples is a debate that is taking place within contemporary ethnographic processes including Denzin's interpretive interactionism and performance ethnography that include a particular emphasis on racial discourses (2001; 2002; 2003). In addition to this, policies and recommendations for the formation of indigenous research institutions that support current indigenous research theories and institutions are necessary to move forward in the process of decolonization (Smith, 1999; Battiste, 2000).

Research as Decolonization

The traumas, losses and grief experienced as a result of colonization continue to be experienced by indigenous peoples via the research policies and practices of mainstream/western institutions and organizations (Royal Commission, 2005). The question becomes about how institutions, organizations, communities and societies stop this process of colonization that continues to afflict the most vulnerable members of society.

Battiste (2000) talks about five distinct phases (described earlier), which will be described briefly here, specifically in relation to the project. In the process of decolonization including:

rediscovery and recovery, mourning, dreaming, commitment and action are phases which are often occurring at the same time within individuals, institutions, communities, and society during the processes of decolonization. The rediscovery and recovery phase includes learning about the realities and affects of colonization. The recovery process then begins with Aboriginal peoples discovering their histories and cultures (Battiste, 2000). This process involves reclaiming language, space for indigenous learning, writing, and researching via the creation of indigenous universities and research centers. There is much anger directed at Western educational institutions due to residential school experiences and the legacy that positivist research has left with indigenous communities (Battiste, 2000). Positivist research has misrepresented the history of indigenous people and the appropriation of their cultures, lives, ancestors and experiences (Battiste, 2000). With the creation of indigenous research and learning institutions indigenous peoples can create the space for their voices and visions to be heard.

Battiste's third phase of decolonization is called dreaming and during this phase Aboriginal peoples learn about their history from elders and oral histories (2000). During this phase it is particularly important for Aboriginal peoples to be cognizant that they do not simply put Aboriginal people into positions or roles that have been maintained by colonizers (2000). Some local examples of this engagement in decolonization include the process of renaming AIDS Prince George and restructuring the research department at CINHS to in the early 2000's. I volunteered with both organizations during those years and during the renaming and restructuring processes both organizations made sure to involve consultation with Aboriginal elders and community forums to include all voices from the communities. Both organizations also involved and continue to involve consultation with Aboriginal elders in the re-vamping of their internal policies and procedures to reflect indigenous cultures and traditions.

Validity within Ethnography

One of the questions outlined for this thesis was to address the issue of how the qualitative paradigm addresses the issue of objectivity through researcher physical, emotional and interpretive distance. This is a difficult question to answer in the context of working with indigenous peoples as the very goals of research include not being objective, being respectful by engaging in meaningful interactions with participants and to ensure that the study/research/work that is being done is work that has a social conscience. It is important in this context to maintain openness to the process of research that may involve personal pain and philosophical angst for the researchers and participants in addition to challenges in methodological epistemologies within Western institutions of knowledge.

Positivistic and ethnographic research paradigms have very different ontologies, epistemologies and methodologies. While the positivistic paradigm relies on the beliefs that the world is very describable, predictable and external to the researcher, contemporary ethnography relies on the assumptions that the experience of research is subjective (for the researcher and participants), and that it is this subjectivity that often informs the research and provides depth of meaning and understanding. Positivism also considers that there is one single objective reality in which participants' experiences, words, and lives can be categorized and labeled context free (Kaboub, 2002). There are many more differences between the paradigms and the debate over which paradigm to use and which is more or less valid and reliable are debates that are not likely to be definitively resolved any time soon. Clearly, comparing and contrasting two dichotomous research paradigms is a very simplistic and shallow way to demonstrate that one method is generally 'better' than the other. This is not the debate because there are many positive aspects of positivist and quantitative methods in research and generally using a mixed methodology is ideal and will produce more complete data (Creswell, 2008). I have decided to use a contemporary

ethnography method of research during the interview and research stage of this project. I believe that doing research with Aboriginal women needs to come from a place that is not engaging in positivist methods that have contributed to colonization. I would like to engage in research that is meaningful, ethical and contributes to the process of decolonization for indigenous peoples. Practicing from a contemporary ethnographic framework including interpretive interactionism, performance ethnography and cultural studies is congruent with these goals. This does not mean that quantitative methods cannot contribute to decolonization and in fact the analysis section of this project includes utilizing a thematic analysis, which includes a quantitative coding process (Braun & Clarke, 2006). In addition, the findings section includes quantitative descriptions of the interviews such as: 6 of the 8 participants noted 'x' as a strength of theirs.

It is important to remember that colonization of indigenous peoples is not a thing of the past and that research and the paradigms utilized play a massive part in the perpetuation of colonization and/or the process of decolonization. It is with these principles and ethics in mind that I have chosen to have cultural studies and Battiste's (2000) and Smith's (2001) processes of decolonization inform the research methodology and design.

CHAPTER FIVE: METHODOLOGY

> From the vantage point of the colonized, a position from which I write and choose to privilege, the term 'research' is inextricable linked to European imperialism and colonialism. The word itself, 'research', is probably one of the dirtiest words in the indigenous world's vocabulary (Smith, 1999, p.1).

As a white skinned Métis woman, it is important for me to feel that the work I engage in is by and for Aboriginal women, rather than being an extension of colonization. This is an ongoing struggle and is partially being worked through via interacting and documenting experiences with nature via photographs, journal writing and by carving. The struggles that I have in engaging in meaningful research that contributes to the process of decolonization for Aboriginal peoples are internal struggles of self-doubt. I worry that this research won't contribute to any greater understandings for the participants; that this will not contribute to the process of decolonization and that people will continue to not care about the health and well-being of Aboriginal people in our society, and question around my 'right' as a white skinned woman to do this work with Aboriginal women. Lawrence (2004) talks about the struggles with being of "mixed blood" in her book and she demonstrates that it has been the processes of colonization that have been responsible for removing the identity of mixed blood people. This has been helpful in reconciling my own feelings of racism and this also situates me in the research as the Aboriginal participants that may be of mixed blood may have experienced or experience many of the same feelings that Lawrence discusses (2004).

Ethnographic Research Paradigm

In her book, *Becoming an Ally,* Anne Bishop notes that social systems and institutions are in place to preserve the status quo. Injustice and inequality are held in place through political, economic and ideological power, as well as through physical force (1994, p. 51). Contemporary ethnographic research directly subverts "power-over" systems of colonization by contributing to

the subversion of Western ideological power. Marginalized voices have a place to claim space and identity. The ethnographic researcher is in a position to provide a forum for voices that would otherwise be silenced, to create a safe space for participants to confirm and interpret their own validity, and in doing so, reality can be accorded by the individuals living it rather than through the continuation of historical rhetoric and stereotypes.

My desire in implementing contemporary ethnographic research methods in this study includes the desire to have meaningful (determined by the participants and I) open-ended interviews at a spiritually significant, safe, nurturing place. The participants themselves chose the Central Interior Native Health Society as the location for the interviews. It was also very important to emphasize strengths within the participants that emerge from the interviews. The interviews also took take place within a fairly short time of each other (two consecutive days) to help ensure that the interviews are not informed by external events in the participants lives or in my life.

Data collection and analysis

Sample

Participants were recruited via a snowball sampling with a poster advertisement at Positive Living North, Central Interior Native Health Society, at the Northern Interior Health Unit's Communicable Disease Team, the Needle Exchange and by word of mouth (Sherman & Reid, 1994). Snowball sampling is an interactive sampling process whereby participants lead the researcher to more prospective participants who have similar experiences within the scope of the research (Monette, Sullivan & DeJong, 1986). The poster included selection criteria such as: the participants must identify as women, as Aboriginal and as HIV positive.

The contact person on the poster was a colleague at the University of Northern British Columbia who is familiar with the downtown community through her own research; however, I chose not be the contact person due to the fact that I have had a number of roles, both paid and volunteer, in the Prince George HIV community for a number of years. As a result, I know a number of potential participants and I did not want this to influence participation in this project. The hope in choosing an alternative initial contact person was that the perceived and/or real power dynamics that are involved may be minimized at the point of deciding to participate or not.

Data Collection

Data for this study was collected via open-ended interviewing conducted face to face with participants. I chose to invite participants to engage in open-ended interviews at this point as I wanted to have some general topics identified for discussion prior to commencing the interviews. Open-ended interviews are "based on the assumption that meanings, understandings, and interpretations cannot be standardized; they cannot be obtained through the use of a formal, fixed-choice questionnaire" (Denzin, 2001). This type of data collection is something that I hoped would meet the needs of the Aboriginal women participants. Open ended interviews also facilitated discussion by the pure nature of open-ended topics. Oral conversations were recorded with permission of the participants and transcribed into text.

Interviews

As noted above I planned to utilize open-ended questions and also introduce specific topics to the discussion such as: strengths of aboriginal women with HIV, the role of helping professionals, needed resources and resources that are particularly important to the participants. Upon reflection and much discussion with peers and Dr. Transken, it was decided that I would construct several questions and, if needed, these questions would be utilized to inform the topics

above. This decision was made in the best interest of informing the research and focusing the participants on topics related to their experiences living with HIV and AIDS as Aboriginal women living in a northern context. Please see Appendix B for questions constructed for the interview process.

Data was collected via digital recordings of the interviews, which were then transcribed. All identifying information of the participants was left off of the tape names and transcription encoding and a code name was utilized instead.

Ethics/Confidentiality and Consent Forms

All issues regarding ethics followed the policies and protocols of the UNBC Research Board and received formal Research Ethics Board approval. The British Columbia Association of Social Workers Code of Ethics (British Columbia Association of Social Workers, 1999) was also followed. Ethics also included notification of the availability of counseling, and services that may be needed as a result of the study and/or that emerge during/after the study.

Confidentiality is crucial with any population and especially when working with a population that has often been colonized through appropriation of culture, resources, identities, and people during the research process (Battiste, 2000; Smith, 1999). For this study several methods were utilized to ensure confidentiality. Participants were asked to consider altering their names and other identifying information prior to interview recording. There is no documentation linking the interviews with the actual identities of the participants. Please see the consent to participate and confidentiality forms in the appendix section of this project.

Transcription/Honorariums

Participants were notified, via the poster calling for participants, that there was a fifty-dollar honorarium for participants engaging in this research study. The honorarium was provided by the researcher and it was made very clear at the time of the initial discussion around participation

that there will be no expectations around content of interviews, etc. to 'qualify' for the honorarium. There were no expectations that the participants engage in the follow up process in order to qualify for the honorarium.

Upon completion of the interviews, the resulting tape-recorded dialogues were transcribed by the University of Northern British Columbia's transcription services. These transcribed interviews were numbered and pseudonyms were utilized for each participant in order to further ensure confidentiality of participants. The taped and transcribed interviews are stored in a combination safe at the researcher's home and upon the conclusion of five years all information will be completely destroyed.

CHAPTER SIX: FINDINGS

Introduction

I interviewed eight women for this project. All of the women interviewed identified as Aboriginal and that they had been diagnosed with HIV. All the women involved in this project stated that they experienced social and economic marginalization as a result of being HIV positive. The women interviewed were very eager to share their stories in the hopes that they could serve as role models and that their stories could help others. They were also very clear that they were thankful that this research was being done and that they wanted to be involved in any research that may help inform helping professionals and the general public about their experiences.

The transcribed interviews were analyzed using a thematic analysis that included five different phases (Braun & Clarke, 2006). During the first phase I read all of the transcripts in their entirety three times, noting some initial ideas and familiarizing myself with the data. In the next two phases, initial coding and themes were developed and then refined in the fourth phase of analysis (Braun & Clarke, 2006). At this time I noted that a number of the coded data sets filled out the content of the data by becoming sub themes of the main themes. At this time the final phase of analysis, involved defining and naming the themes and sub themes (Braun & Clarke, 2006). This process of thematic analysis of the transcripts of the women's interviews identified five main themes: support, resources, identity/life meaning, northern obstacles and strengths. The five main themes are further separated into sub themes as outlined in the following table:

Table 1

Themes Developed from the Transcripts

Support	Resources	Identity	Northern Obstacles	Strengths
Peers	Useful/Positive	Role Model	Cold	Woman
Family	Missing	Peers	Transportation	Aboriginal
Professionals	Limited Hours	Helping Others	Nutrition	Tenacity
			No anonymity	Optimism
			Housing	Spirituality Religion

Support

During the interviews the most common source of strength that the women talked about was the supports in their lives. Supports most often mentioned and most crucial to the women included peers, family and professionals.

Peers

Peer support was mentioned as a source of strength in seven of the eight interviews. There was a sense that there was an identity and support in being identified as someone from the downtown core. There was a sense that people looked out for each other and more than one respondent talked about knowing each other and forming their own support system (Gina, Christina, November, 2010).

One respondent in talking about her peers stated that:

> They'd do anything for you – they give, they'd give you the shirt off their back, and the last change in their pocket. I feel emotional. But, I've realized that no matter how much support I go and try and find, its always the street people that are there to open up their arms (Morina, November, 2010).

Robin also talked about the importance of having peers as supports and in particular peers also experiencing the effects of being HIV+:

> Because a lot of people don't understand the situations in our lives that come and go with HIV. We know how we hurt. We know how we feel, and we know how weak we are and stuff like that and these things are important. I mean, its not just some place to hang out, its some place to be with each other (November, 2010).

The women talked about a number of things with peers that made them feel supported including that no matter what time of day or what day of the week it was they could always find someone that they could spend time with and feel supported.

Family

Not all of the women interviewed had access to their families nor did they feel supported by their families. The participants that did include talking about the importance of family members discussed growing up and having someone to support them and to hear their stories now.

Penny talked about going back to her home community and having her brother in attendance as she told her story:

> I'm part of the positive prevention every Wednesday and I do educational trips in, on other towns too. I went to my hometown and um, I got, I got a good response from my hometown. They supported me. And my brother he didn't, as soon, he was right up front listening to me and what I felt from him, he wanted to hear my story, how I got HIV. And he stood there. He sat there and he listened to my whole story and I was happy. Like a long time ago he said he had a lot of respect for me. And it was true and he proved it and I was happy. And, I got lots of support from my family (November, 2010).

Family was also mentioned as a source of support for Jenny when she decided to take care of her health: "It's got a lot to do with me not being able to have my kids. My kids are number one priority in my life" (November, 2010). Jenny continued on to say that "being able to, um, access my nephews, nieces and nephews. Number one priority may be this. That's my strength"

(November, 2010). Family and strength were also themes for Robin when asked about where she felt her strength came from: "Certain family members who have been helping me, like go from plan A to B, like sister and aunts and stuff like that" (November, 2010). When asked about her strength and where she learned this from Gina responded "like, it's pretty much like role models, like parents and, you know, other friends, other family members, you know" (November, 2010).

Professionals

> Yeah, I need, I don't really have any family per se, other than the family that I have at PLN. You know, um, like it doesn't take blood to make family and it seems like those people and the staff here at the clinic [CINHS], are basically the ones that look out for my best interest and, and they worry about um, if I'm going to be okay and whatever (Marilyn, November, 2010).

Most of the women talked about feeling really supported by staff and in particular staff at Positive Living North, Central Interior Native Health and the Needle Exchange. Robin talked about her strength coming from "partially, some of the services I've been receiving from certain people I love, people I – certain staff members that go out of their way to get help for me" (November, 2010). The women further talked about feeling cared about and how crucial this was to feeling welcome. When asked about what was helpful with the staff at the Needle Exchange, PLN and CINHS Marilyn said "because they care, truly care. I can feel it. Yeah where it comes from the heart and soul. Where they've got one" (November, 2010).

Jenny discussed that she likes accessing the resources at PLN and CINHS because "the people here, they do whatever they can to help you. I feel welcomed. That they care. Accepting me and whoever, you know. They accept people for who they are. Not what they do" (November, 2010). She specifically talked about the people at PLN: "The people that are there, they do whatever they can. And I realize that they're, you know, there's not enough of them to help everybody. And my heart goes out to the people that do try and help us" (November, 2010).

When asked what she found helping in accessing resources such as PLN and CINHS Marcy stated "people being helpful and friendly and letting me know that they are there for me when I need them" (November, 2010).

Resources

The topic of resources came up in eight out of eight of the participant interviews. All of the participants identified positive resources in the community that they access including Positive Living North and Central Interior Native Health Society. A few of the participants also talked about the Needle Exchange, New Hope Society, the Native Friendship Centre and food banks. Most of the participants also identified resources that are either missing from the community or simply that more are needed.

Positive/Useful

Positive Living North and Central Interior Native Health Society were discussed by all of the participants as very positive resources and that these agencies are a very important source of support for them. The Needle Exchange, New Hope Society, the Firepit and the Native Friendship Centre were also mentioned by some of the participants as places where they felt welcomed and cared for.

Penny talked about her experiences with PLN and CINHS and that:

> They're always willing to help. They always inform me about things coming up and they want to know if I wanna participate in it. And I feel so pleased that they chose me and it, I really deserve it. They want me. And it, you know, gives you a good feeling inside. These guys make me believe in myself (November, 2010).

Gina talked about the things that she found helpful about going to Positive Living North:

> It's very helpful because you know there's people there that you can talk to and, you know, you need to have your friends there – like if you're having a bad day you can just like walk up to somebody that's there, just somebody to talk to (November,

2010).

Christina, Gina, Robin, Penny and Marilyn all talked about the importance of having a space in which they could spend time together and that the drop in space at PLN provided this for them. Some of the important pieces mentioned about the space included having a space to sleep, watching television, having a meeting space specifically for HIV positive people, having members meetings and knowing that you have a place to and that there will be someone there. A few of the interviewees did mention that the drop in space wasn't open as often as it used to be and that they would like a 24 hour space to spend time (November, 2010).

When asked if there were anything else she wanted to talk about Morina stated: "These guys [CINHS] are doing an awesome job" and that CINHS have "been always helpful and open arms" (November, 2010). She further identified that reminding her about her medications and about upcoming appointments is particularly helpful (November, 2010). I then asked what it felt like when they reminded her of her appointments and Morina stated: "Yeah, like wow, somebody actually cares" (November, 2010).

Missing

While all of the interview participants talked about positive resources in the community, they also talked about some things that they think would be helpful. Transportation, food, and housing were mentioned as resources that are needed in the community and they are talked about in the Northern Obstacles section. Other needed resources identified by the respondents include an HIV positive counsellor, space for persons with HIV that is available twenty-four hours a day, weekend counselors, more advocates, more community education about HIV and education for persons that are affected by friends, partners, family that have HIV.

Marcy talked about the need for more HIV education for the general public because "they don't learn about it. They just think that, you know, because I got it I shouldn't use the bathroom,

I shouldn't use utensils. Yeah, they don't realize that they can't get it like that" (November, 2010). Other things that Marcy thought would be helpful for her in the community included activities "like going to the movies, going swimming, you know? Doing stuff like that *with* us. That would be a lot more helpful" (November, 2010).

Morina talked about her experiences with people after finding out she was HIV positive and the need for more education:

> And I was just mad that the information or anything going around about HIV and I think that's when people look down on you. And cast you out as the, as the yeah, someone with the plague. I mean like, you know, we have to live in the now – I mean there's lots of people living with HIV and there's just not much people coming up to talk about it because of the fact that there's not much information out there for people that don't know anything about it. I mean to them you can catch it by hugging or sharing (November, 2010).

Three of the women talked about the need for an HIV counselor that is HIV positive. Robin talked about having another counselor to talk with "maybe somebody with HIV, not just a counselor but counselor who's familiar with HIV and living with it. Because he would know the way we are" (November, 2010).

Morina talked about part of the problem being that even commercials depict HIV as "kind of like really scary" and "that's what makes it iffy for women like us, come forward, and say 'hey yeah, I live with it' you know" (November, 2010).

Jenny felt that there were long waitlists to see a doctor and that there appeared to be a need for more doctors at CINHS and the need for "schooling available to affected family members. Give [them] some kind of understanding. And help them to realize that you know that they don't have to be scared to breathe or" (November, 2010).

A few of the women discussed the desire for more activities, group outings and to be kept busy on the weekends as this is often when they are struggling the most. "I find the weekends

very hard. I feel stuck and lonely on weekends. There's nothing to do" (Marilyn, November, 2010). Marilyn and Marcy both talked about wanting to go out to Camp Friendship for a group camping activity with Marilyn stating:

> Well, they have this place, Camp Friendship out of town and I would like to see more people spend more time going out there, if we had proper um, if the place was up and running and you didn't have to get a cook and get this and get that. Um, I wouldn't mind. They go to some place like that rather than being stuck over them times. You know? 'Cause whether its winter, spring, summer, or fall the older I get without a vehicle it seems, it seems like, yeah, there's nothing to do (November, 2010).

Identity

Seven of the eight women talked about their role as a friend or peer during the interviews. They also talked about being role models for youth, and that part of their identity and strength came from their family members. Some of the women discussed being a Frontline Warrior (program run with PLN) in the fight against HIV/AIDS and that this was an important part of their lives.

Role Model

When asked about her strengths Robin talked about part of that coming from being a role model and "doing pilots with PLN to be a front line warrior in the fight against HIV" (November, 2010). Marilyn also talked about the importance of being a role model to youth and that she has a strong sense of belonging to the community and that "everybody, you know they say, Marilyn a.k.a. 'mom'" (November, 2010). When asked if this role was important to her Marilyn stated that it was and that people who have moved out of her housing complex say "I wanna move back to where 'mama' is [laughs]" (November, 2010).

Penny also talked about her peers and wanting "to be a good role model and part of a positive example so I can do, so I can be healthy towards (inaudible). I like being part of positive

prevention because I see my peers shared, I see my peers share my story and it helps them to relate my story to theirs" (November 2010). Morina was clear about having a positive impact on her peers "because a lot of people look up to me...and the thing is I brighten everybody's day and I mean like if I can change my life and turn it around, you know, who else you know will come and follow?" (November, 2010).

A number of the women interviewed discussed their desire to be a positive role model for their family members. Penny and Marilyn both talked about wanting to be positive role models for their mothers and for their children so that they didn't make the same mistakes that Penny and Marilyn felt led to the contraction of HIV (November, 2010). Robin also talked about wanting to be a positive role model to her family members:

> My nieces, my nephews – this is one of the reasons why I do these exercises and explain what I know, and one of the reasons why I did the video I shot [prevention video] because I want my family, upcoming family, my nieces/nephews, brothers and sister I had growing up, to know and to be aware (November, 2010).

Penny mentioned the importance of role models a number of times during our conversation and shared an excerpt of a written letter that she shares with the youth highlighting being a good role model: "Stay safe. Use protection, and learn how to speak up for yourself and be an example and role model for others and hang around those that are honest and treat you how you wanna be treated" (November, 2010).

Helping Others

The women interviewed all had some notion of helping others whether that was their peers, family members or by educating youth and their communities via telling their stories. Some of the women also had the sense that they became HIV positive as part of their journey to helping others. Jenny stated that: "I believe that He's given me this sickness because he wants me to help

others. I would love to travel and let other HIV people know that you know, they don't have to take that road where they think they're gonna die anyway" (November, 2010).

Penny talked about her experiences working as an educator for youth in middle schools: "I try and participate in things like education, teaching grade um, grade nine and ten about HIV and staying safe. And I, I'm part of the positive prevention every Wednesday and I do educational trips in, in other towns too" (November, 2010). When asked what she hoped for out of talking with the youth Penny responded that "I hope that they find good friends whose, who are role models and set a good example" (November, 2010). Robin also talked about how important it was for her to participate in research and awareness projects like this one and that it was helpful for people with HIV (November, 2010).

Northern Context

Working as a social worker for twelve years, a Northern context researcher for eight years and the Executive Director of a large multi-million dollar non-profit community services organization for almost five years in the North, I have learned that there are a number of differences in service delivery compared to urban or southern regions. The difficulty is that funding is often based on the same formulas that are established in urban areas causing gaps in service in the North (Hemingway in Williams, 2010). The women interviewed were very aware of these realities with seven out of the eight interviews containing service or resource obstacles that are particular to or exacerbated in the North. The most frequently mentioned topics included transportation, nutrition, housing, lack of anonymity, and the cold weather.

Transportation

Transportation was seen as a barrier for most of the women around accessing resources in the community. Some of these resources included medical appointments, going to the pharmacy for medications, accessing food banks/meals, attending counseling appointments and general

everyday errands. When asked about her experiences living with HIV in the north Robin talked about being generally weak and that a better transportation system would make her life much easier:

> We are generally weak. A lot of times we can't move as fast as people, like it took me all this morning to get to here [laughter]. And uh, we need rides to places – that's a really important thing. I went to welfare five times in a week and you know how much that takes just to get up and do that? Like get up and walk there? I mean, they don't know what they're putting me through (November, 2010).

Marilyn talked about the "bus system being nothing like the coast" and that because she has to walk everywhere with a physical disability she is afraid of falling and freezing to death and listed this as "my greatest fears of them all" (November, 2010). Penny also talked about the difference between being in the North and living in a larger urban centre:

> Well, and the buses should run more 'cause some of us have physical disabilities and the buses should run more on the weekends. And holidays. Like in Vancouver it's every ten, fifteen minutes and that's (inaudible) [laughs] point A to point B real fast. You don't need a schedule. You don't need to look at your watch. That's nice (November, 2010).

The women that did discuss transportation, listed having access to the bus or rides to their appointments as one of the simple solutions that would have a practical positive impact on their lives. Jenny talked about the support that she gets from agencies and her first point about this support was that "they take me to my meetings and doctor's appointments" (November, 2010).

Nutrition

All of the eight women interviewed live on very limited incomes. This has a negative impact in their lives in a number of ways including their ability to purchase or access nutritious foods. Six of the eight women actually talked about having difficulty accessing nutritious or enough food during the interviews with three of the women stating that this was more of a barrier in the

North. The other three women had never lived outside of the north so were unable to comment on whether this issue was worse in the North.

Christina talked about different resources in the community and that one of the important things for her was Positive Living North's Friday night client meetings because "on Fridays we get to have supper, not supper, they actually cook something for us" (November, 2010). Christina also mentioned that one of the reasons that she accesses programs there is because "they have a lunch and breakfast program" (November, 2010). Morina also advised that the food vouchers at Positive Living North are one of the two things that she accesses there (the other being blood analysis) (November, 2010).

When asked about what she felt were important pieces around being HIV positive and living in a Northern context Robin responded:

> Well, for one we need uh a high volume of certain kinds of foods, I mean, nutritions. We try to get that from the food banks and stuff like that and they won't give it to us because we're single people. And if we had partners that died of the same thing or whatever but, a lot of times they won't help (November, 2010).

When asked again if Robin's experience was that this was more difficult in the North than the lower mainland or larger center's Robin responded that "yeah" this was her experience (November, 2010).

Food such as muffins, fresh juices and homemade fruit and cheese scones were available to the participants and when asked if Marilyn would be able to make use of the rest of the food by taking it home she responded: "you're damn right!" (November, 2010).

Housing

This writer didn't specifically ask the participants if they felt that housing was an issue for them but, three of the participants brought this topic up specifically and another participant alluded to housing as an issue.

Marilyn and Penny both talked about wishing that there was a housing facility that was specific for persons with HIV and Hep C and while Marilyn is glad to have a place she described it as the size of the small office that we were in: "so that's my whole room is this size" (November, 2010). Jenny talked about the need for better housing and in particular she felt that "there should be more advocates" for things like housing, and transport (November, 2010). In discussions with Morina she talked about the need for housing: "And it's, it's hard because I mean, like, because I said we sleep outside sometimes just to be with each other and now it's getting colder. I mean like it's not fair" (November, 2010).

Although Christina didn't specifically state that housing was an issue for her, she did advise that one of the reasons that she accessed PLN was so that she could have a warm place to sleep (November, 2010).

Judgement

Six of the eight interviewees talked about the lack of anonymity living in the North and how this impacted them. When asked about being an HIV+ aboriginal woman in Northern BC the first thing that five out of the eight interviewees talked about. Penny stated: "Well you sort of get a feel of who knows what about you. Where you hang out and um, you know some people, they know you have HIV. They just stare at you and talk behind your back" (November, 2010). Robin talked about similar experiences living in smaller communities such as those in the North:

> Basically walking through those doors downtown, being such a small town in the north, everybody sees where you're going. Because they're more observant than they would be in the big city, you know what I mean. We're being observed going into an HIV positive place, so we're really [inaudible] because everybody knows (November, 2010).

Jenny also talked about everyone knowing about being HIV positive because of the agencies that she accesses and that "a lot of people judge you because you have HIV. And, I don't know.

It seems to me that people look at you like you're dirty" (November, 2010). A couple of the women also talked about their experiences with professionals and though they felt that most professionals kept confidentiality they did have experiences in which they felt their HIV status was not kept confidential:

> Like it stops me from going certain places. Because who wants to go and let any of them people know anything about you when all they're gonna do is when you sit down you know that they're making those eyes and they're laughing and they're talking about you. People like that shouldn't be working in public or, you know, there's gotta be nicer people that believe more in confidentiality (Marilyn, November, 2010).

Cold

When asked about how being HIV positive in the North has impacted them half of the respondents talked about the cold weather having a negative impact on their lives. Robin talked about having HIV means that "we're constantly cold to begin with. I mean we (inaudible) because of our, our sweating. We're damp and then we, and then, just a slight chill will freeze us" (November, 2010).

Marilyn and Penny both talked about the fact that living in the North means that you are living in a colder climate with Penny stating: "It tends to be a lot colder there, then and slipperier and on those days my bones and joints ache way too much and I need to be handles with care" (November, 2010). Marilyn talked about transportation to appointments being even more crucial in the cold weather in a Northern climate: "Um, going to help me get around. You know as far as getting my meds and everything, yeah. Being it's that time of year, that's that last thing I need to do is um, freeze up somewhere" (November, 2010).

Strengths

All of the eight women interviewed were able to identify areas of strength that they described as something that they had always had, a strength that they became aware of after their HIV diagnosis or a strength they became aware of as a result of their HIV diagnosis.

Woman

The topic of being a woman and the relationship to strength came up in four out of the eight interviews. Some of the strength discussed as a result of being a woman included the role of being a caregiver. Robin, talking about her woman strength, stated: "I think it's related to not wanting to see your mate or your siblings hurt or vulnerable or have to go to somebody else, where they could, where I could provide. So, I wouldn't have that, I would fight even though it took everything I had in me" (November, 2010). Robin further stated that she "wanted to be the person that they needed, that they could depend on. Even though I was weaker and I was the one that was always looked down on because I was a woman" (November, 2010).

> Because women were always uh, stood to take second place in line against a man and in these days, we're more the bread winners, we're more like the fighters. Like when my husband was alive, he was weaker than me, so I would tread forward and fight and push him and pull 'come, you got to go, you got to do this, you got to do this and we got to do this. You know? And I would tread on (Robin, November, 2010).

Other interviewees talked about learning how to be strong from watching their mothers survive domestic abuse, raising large families on their own (Robin watched her mother bear and raise 24 children), living in poverty and yet surviving or escaping these circumstances. Jenny talked about learning about strength from her mother and when asked if she would describe this she stated:

> What I mean is that she – I grew up watching my dad beat on my mom, and there was always, um, violence. My dad was really violent towards my mom. And for my mom to raise five kids was

> just phenomenal. But she had to leave my dad to get away from everything and everybody. And watching her do that made me realize that, you know, if she can do it, I can do it (November, 2010).

Penny talked about gaining strength from becoming a mother, wanting to be a strong woman role model for her daughter and for her foster mom and "I have a feeling that the Creator wants me to speak up for women's rights" (November, 2010).

Aboriginal/Spirituality

A few of the women interviewed talked about wanting to learn more about Aboriginal spirituality but, that they were afraid to because they had such mixed understandings of their own identity:

> I had a tough life growing up. I went to 27 foster homes, sexual abuse, physical abuse, I mean for the longest time I thought I was white because I stayed in white foster homes. When I was in grade school they said something about stupid Native kid and I'm like "I'm not Native!" and this little white boys like "yes you are", I'm like "no I'm not, I'm white" and he's like "look at the color of your skin" and I was like, I was shocked. I was like what the hell? Like I never knew anything about Natives. Still don't. But, I mean I would love to. I think I'm too scared. I don't want to offend anybody (Morina, November, 2010).

Robin talked about both her family and spirituality as pieces of her strength: "Yeah my family always taught me to go on no matter what. Yeah and being, coming from a Christian background, like my families are Christians and we believe in the Lord very highly about everything. And that's what keeps me fighting" (November, 2010). Marilyn also talked about family and faith helping her with her strength: "There was um, in my dad's first marriage, with his first wife um, the one that wanted me, the mom that wanted me. And she was really strong Catholic and her family is too. Then, but I kept, I've always been basically spiritual myself" (November, 2010).

When this writer asked Penny about her strength she responded that "I pray. My mom taught me to pray and I listen to her. All the things like there…I learned to let it go and I forgive them 'cause my mom taught me to pray. And is seems like my prayers are answered every day and it makes me smile and it makes me laugh" (November, 2010). Penny also talked about using journals as part of her spirituality and that she addresses her posts to both "Dear Father" and "thanking the Creator" (November, 2010).

Marcy was asked about her strength and what helps her with this and she stated that "I smudge, I pray. Native spirituality, it is very important. It helps a lot" (November, 2010). This writer asked what Marcy found helpful about Native spirituality and she stated "I don't know, it's just believing I guess" (November, 2010).

Optimism

All eight women were somewhat philosophical and optimistic in relation to being HIV positive. They also connected their optimism to one of their strengths in continuing to deal positively with life circumstances.

> I just learned to live with it and I don't think it's going to be the end of the world anymore. I just learn to accept it because not I look at it as if I'm going to live like that, thinking 'Oh, I'm going to die' and everything's over, I'm just going to die a lot faster because that's negative thinking right? But, if you're straight and thinking positive about it and not even worrying much about it, I'm pretty sure you won't get as sick as you really would if when you have negative thoughts right? (Christina, November, 2010).

"'Cause you got HIV or whatever doesn't mean that your ship has sunk" (Marilyn, November, 2010). Penny also talked about being let down by her mother when she was younger and that she learned that she would never do that:

> My mom may have done that [disown me] to me when I was younger but, but I would, it's something I learned from my past. I wouldn't do it to somebody else. Because you're a human.

> Everybody deserves a fighting chance and if, not only once but it's ongoing. It's how you learn (November, 2010).

"I just hope one day they realize that HIV isn't about death" (Jenny, November, 2010).

Summary

Eight women were interviewed to discuss their experiences living as HIV positive Aboriginal women in northern British Columbia. After analyzing the interviews five major themes emerged: support, resources, identity, northern obstacles and strengths. In summary, the women talked about the services that they currently access and how supported and cared for they felt. They also provided suggestions regarding resources that they felt would be helpful to them including a better transportation system, greater access to housing through advocacy and having access to an HIV positive counselor. I have worked as a social worker in northern British Columbia since 1999 including working at the Needle Exchange, volunteering at Positive Living North, volunteering as a Board member at CINHS and the Sexual Assault Centre, working as a mental health and addictions counselor and, for the past almost five years, working as an Executive Director for a community services non-profit. During this entire time the same issues have come up as barriers for persons living with HIV including transportation, housing, access to resources, and access to medical specialists. All of the women interviewed are incredible, strong women who have experienced some level of discrimination either based on their gender, ethnicity, HIV+ diagnosis or a combination of these. Despite this, each woman spoke of her strengths, and optimism and during the interviews all were consistently generous with their time, vulnerability and this writer. It is unfortunate that they spend so much of their time just trying to survive and access what little resources are available to them.

Funding for programs for Aboriginal women who are HIV+ continues to be incredibly inadequate and lacking a focus on holistic wellness. Funding formulas continue to ignore the

reality that it is more expensive to deliver services in the North and more difficult for participants to access services in the North. This is due to the vast geographical distances to cover, lack of infrastructure and the reality that Northern centres do not have the economies of scale that are available in larger Southern centres (Hemingway, 2010). This is not likely to change anytime soon despite the frighteningly high rates of infection for Aboriginal women in northern British Columbia. Governments must increase funding, and in collaboration and consultation with Aboriginal entities, establish the most effective treatment and supports for persons with HIV. In the meantime, the resources listed in this project are commended for the efforts that they make and the relationships that they have established with each of the women that participated in this project. In addition, it is vital that they continue this work and continue to provide these exemplary services and support to these women.

CHAPTER SEVEN: SUMMARY AND RECOMMENDATIONS

Health Canada acknowledges that the high numbers of Aboriginal persons infected with HIV is at least partially attributable to colonization of Aboriginal peoples in Canada (Health Canada, 2005). Although Aboriginal peoples represent 3.3 per cent of the Canadian population they account for 12 per cent of all HIV infections (Public Health Agency of Canada, 2007). The infection rate for Aboriginal peoples is approximately 2.8 times higher than non-Aboriginals and specifically Aboriginal women account for approximately 45 per cent of new infections (Public Health Agency of Canada, 2007). These women need services such as CINHS, Positive Living North, the Friendship Centre and the Needle Exchange to be there when they are diagnosed and subsequently living with HIV.

Information from the literature review and the analysis of the data collected from the eight women interviewed, recommendations for moving forward include: maintaining/increasing supports/services, highlighting the realities of a northern context, continuing to lobby for increased funding that supports decolonization all the while incorporating the women's self-identified strengths. While much of the research and literature review in this endeavor has focused on what we, as communities, organizations and helping professionals are not doing, it is also crucial that we acknowledge pieces of strength and hope for the future around the processes of decolonization that are happening in and around us. By actively listening to and advocating for the inclusion of Aboriginal voices in the services or organizations with Aboriginal and First Nations priorities we are significantly engaged in the process of decolonization.

Maintaining and Increasing Supports and Services

A number of services were identified by the women interviewed as very helpful and necessary for them to be able to access. Drop in space was identified as a key supportive space for most of the women. They talked about the need to have a space specifically for persons with HIV so that they could meet up peers, participate in members meetings, have a safe space to sleep and just simply a space that they know they can go to and have someone to talk with. The drop in centre at PLN was identified as a space in which all of these things were available. A few of the women advised that having this space open 24 hours a day and seven days a week would provide that atmosphere all of the time and this would contribute to their safety.

The Frontline Warriors program run out of PLN was also identified as particularly helpful and a few of the women talked about this in the context of feeling like they were helping others by participating in this program (Penny, Robin, November 2010). Having opportunities to participate in prevention work was acknowledged as an important piece of identity by a couple of the participants (Penny, Jenny, November, 2010). Re-creating identity in an Aboriginal context such as the Frontline Warriors program by telling their stories as Aboriginal women is also an important component of the process of decolonization (Battiste, 2000). Battiste further explains that in reclaiming identity there is a need to be cautious that Aboriginal people are simply not taking the identity of the colonized and that they in fact ensure that the identity is based in traditional Aboriginal knowledge and cultures (2000). PLN demonstrated this dedication when re-naming their organization to reflect an Aboriginal identity. PLN engaged in the process of consultations with local elders in determining a name that would reflect the identity of local Aboriginal peoples resulting in: No kheyoh t'shi'en Society.

Blood work and medical services out of CINHS, PLN and the Needle Exchange were also identified as important services to the women involved. Seven of the eight women also talked

about the reality that the professionals they worked with at CINHS, PLN and the Needle Exchange were an important source of support in their lives (Jenny, Penny, Marcy, Marilyn, Robin, November 2010). The women talked about the atmosphere being really important including the feeling that the helping professionals actually really cared about them and that the agencies mentioned above do this particularly well.

Peer and family supports are also very important to the women interviewed. Some of the ways in which to maintain these supports include having the drop in space at PLN, encouraging natural supports such as having peers and family members in the women's lives and providing space for participation in group activities. Activities mentioned included participating in group camping trips out to Camp Friendship where the participants could participate in cultural activities. The women also talked about the importance of keeping busy re: maintaining distance from substance misuse and loneliness. Battiste discusses recovery and rediscovery as the first phase of decolonization and the importance of reducing/eliminating substance use and participating in these types of activities fits with this goal (2000). Battiste warns that there is a tendency of Aboriginal people and organizations to look at their traditional cultures from the perspective of the colonizer, which only perpetuates colonization (2000). Both PLN and CINHS pay particular attention to distinguishing between perpetuating colonization and engaging in decolonization by consulting with community elders and affected persons (persons with HIV) when engaging in agency and program planning.

Both organizations are also clear that when researching Aboriginal peoples/experiences at least one of the principal researchers has to be Aboriginal. In addition, my experience as a Board member and volunteer with CINHS and PLN led me to learn and observe that Aboriginal leaders and elders must be involved in steering committees, advisory councils, focus groups and by speaking of their experiences. These practices must be supported and research about and for

Aboriginal peoples must be supported in these ways to support the process of decolonization (Battiste, 2000). Large funding bodies such as PHAC, First Nations Inuit Health Branch, and provincial and federal governments should have similar requirements when making decisions regarding who to award research grants/funds to.

Education about HIV was an aspect that came up in most of the interviews with the eight women. A few of the women acknowledged that there were some educational services offered by PLN, but there were also concerns that the community at large remains ignorant around contraction of HIV and that there was a need to clarify "that HIV is not a death sentence" (Jenny, November 2010). This lack of understanding around HIV and contraction contributed to the women feeling isolated and judged which further kept the women from engaging in their journey to decolonization (November 2010). While the women knew there were some educational opportunities provided by PLN, they also talked about the need for more funding to support more educational programs in the community at large.

One of the suggestions offered during the interviews was to provide educational opportunities for family members and friends of persons living with HIV. Some of the women advised that the lack of understanding of HIV has further isolated them from their families due to fear of contraction and concern for children within their families (Jenny, Robin, personal conversations, 2010). The Royal Commission on Aboriginal People (2005), CAAN (2005) and Battiste (2000) all include education as one of the crucial pieces toward decolonization. The CAAN recommends that this strategy of educating persons is particularly important in northern, rural and remote communities as barriers including homophobia, fear of being identified and lack of access to services exacerbates ignorance of HIV (2005).

Access to a counselor that is Aboriginal and HIV positive was another suggestion made by some of the women interviewed. A couple of the women talked about the counselor then

understanding exactly what they go through living with HIV and AIDS on a daily basis (Robin, Penny, November 2010). It is recommended that schools of social work include curriculum specific to HIV and AIDS in their programming because regardless of whether you work in an HIV and AIDS specific agency the HIV pandemic strongly suggests that helping professionals will be working more and more with persons with HIV and AIDS. It is also important that the women have a healthy, positive, Aboriginal role model that understands traditional healing, colonization and the resulting impact such as high rates of HIV contraction. Battiste talks about access to such a support being important during the first two phases of decolonization because they include discovering facts of colonization, starting the process of recovering one's own history and mourning these realities (2000).

Impact of Northern Context

Much of the funding for HIV and AIDS programming is provided via provincial and federal government funding bodies. Funding decisions within these entities are made within an urban and southern context and few if any concessions are made for the increased costs of service provision in northern communities. This has been consistent with my experience as an executive director of a northern, rural, remote community services agency. In over four and a half years of negotiating contracts directly with provincial and federal government funders it is very clear that the funding formulas are designed for urban and southern communities. These funding formulas do not work in a northern context for several reasons including: lack of transportation options, difficulty recruiting qualified staff, increased facility expenses (heating, snow removal, etc.), increased costs of high staff turnover rates (recruitment and training costs), and vast geographical areas that agencies are required to cover (Hemingway, 2010).

Another reality of working in a northern context is the poor fit between urban educated helping professionals and work with clients in a northern context (Alexander, 2008). This is due

to several factors including the reality that it is very rare for schools of social work to include courses that are specific to social work in a northern context. Several entities including the Canadian Aboriginal AIDS Network (2005), the Royal Commission on Aboriginal Peoples (2004), and the Public Health Agency of Canada (2007) have recommended education and programs specific to Aboriginal peoples' experiences. The Royal Commission has also recommended that part of the process of decolonization is for the Canadian government to establish an International Aboriginal University (2004). Schools of Social Work should be required to have mandatory Aboriginal courses that not only stress Aboriginal peoples' experiences but, to include what our roles are as allies, peers, and helping professionals that contribute to decolonization.

Funding bodies need to take into account the differences in community service work when doing this work in southern or northern communities. The women that were interviewed mentioned the struggles that they have in accessing services because of the lack of transportation to their appointments and that they had to travel to Vancouver to access HIV/AIDS specialists (Robin, Marilyn, Penny, November 2010). It would be in rare circumstances that this would be an expense that can be afforded. Recommendations to change this include funders providing adequate funding based on the real costs of service as opposed to a standardized formula that does not work in the north. Training funds provided by provincial and federal funders also need to recognize the increased costs of providing training in northern communities as providing training is not only ethical service but, training opportunities reduce staff turnover rates and associated costs. This in turn, assists helping professionals make and maintain depth of relationships with persons accessing service.

Helping professionals working in a northern context also have little access to supports such as clinical supervisors not only as a result of inadequate funding but, also the difficulty in

recruiting highly qualified staff to live and work in the North. My experience as an executive director and frontline worker indicates that working as a helping professional in the North means that you are working with little support. When working with populations that have experienced high levels of trauma such as Aboriginal women with HIV, helping professionals are often repeatedly exposed to traumatic life histories, which can result in vicarious trauma. In my experience this often leads to burn out and extended periods of time on leave from work, which again taxes the individual worker, the agency and this often has a negative impact on the clients as they experience the revolving door of counselors. I recommend that this issue be incorporated into an adequate funding schema including the provision of access to telephone clinical supervision and increased funding for persons in the North to get out of the communities to attend trainings and liaise with peers.

Another staffing issue that community service agencies such as PLN and CINHS face is the reality that qualified helping professionals are likely to take advantage of higher paying government/health authority jobs after gaining a couple of years of experience with the community service agency. This is true of my experience in attempting to retain staff as the temptation of higher paying employment, increased benefits and more supports often outweighs the helping professionals desire to remain with a non-profit agency.

Another reality of living in the North the women discussed was the lack of anonymity in accessing services. They talked about everyone knowing that they were HIV positive because they accessed PLN resources and that they felt judged as a result (Marilyn, Jenny, Robin, November 2010). Some of the solutions to this issues include providing more and more outreach services to participants and again, engaging in educating entire communities about HIV in order to erode the negative stigma associated with HIV. These issues associated around living with

HIV/AIDS in the North may not seem complicated but, the solutions will take time to incorporate into rural and remote communities.

Relevance to Social Work

> The trajectory of the epidemic points out the unfortunate reality that sectors of our population are, and have been, left behind while others have benefited significantly from scientific advances. The structures that allow for these disparities are themselves foci for social change (Wheeler, 2007).

HIV has a critical catalyzing function to perform in the present and future direction of social work training. Risk factors related to transmission of HIV/AIDS and subsequent effects of living HIV/AIDS require a multidisciplinary and multi skilled approach to client care and advocacy. In addition, social workers must understand the social inequalities that affect Aboriginal women, the role that colonization has in this disparity and how this continues to impact the women's ability to cope with their HIV infection (McCall et al., 2009). The Canadian Association of Schools of Social Work (now the Canadian Association for Social Work Education, CASWE) has published recognition of this need since a 1988 CASSW article stressed the necessity for social workers' education to include specific skills and knowledge related to service provision for persons with or affected by HIV/AIDS (CASSW, 2009; CASSW, 1998; CASSW, 1988; Gilbert & Linsk, 2002; Roeder, 2002). In January of 2011 I looked at the curriculum (specifically, online course outlines for each course listed in the program) of 15 randomly selected (first listed in a school of social work online search) Canadian university social work programs. I discovered that of these 15 programs one of the programs has a First Nation's specialization and one of the programs has an Indigenous specialization. Exploring these two First Nations/Indigenous specializations further revealed that only two courses of each program's required twenty courses to graduate are specific to First Nations and Indigenous peoples. Further,

not one of these programs offered courses around First Nations and Indigenous peoples and HIV and AIDS. There is some question as to whether smaller social work programs would be able to offer a course within the program that is specific to HIV and AIDS and Aboriginal peoples. This is a valid question and in these circumstances it is suggested that a course on HIV and AIDS focusing on all populations would be welcome. In addition, curriculum in smaller programs can also address the lack of HIV and AIDS focused curriculum by integrating this topic throughout the entire curriculum.

Similar finding by other researchers indicate that the topics of HIV and AIDS tends to be marginalized in the curriculums of schools of social work and helping professions despite the ever growing need for social workers and helping professionals with HIV and AIDS knowledge and skills (Natale et al., 2010; Wheeler, 2007). In the absence of this curriculum, and thus HIV/AIDS pertinent knowledge, some agencies have taken the steps to develop action plans to disseminate this knowledge to social workers (Natale et al., 2010). While this can be an effective strategy for some agencies, it is crucial that schools of social work include specific HIV and AIDS courses and increased curriculum so that graduating students are already trained in specific skills and have an understanding of structural factors that create the context in which the disease thrives (Wheeler, 2007; Strug et al., 2002). As social workers our work is not to simply suggest that the work of HIV and AIDS begins and ends with the individual client, it is to question the structures supporting the disparities that exist as a result of social, political, racial, economic injustices: the legacy of colonization.

CHAPTER EIGHT: CONCLUSION, LIMITATIONS AND FUTURE RESEARCH

I started this research hoping that I would come up with a model, in consultation with HIV positive Aboriginal women that would support creativity, strength and the process of decolonization. I hoped that this in turn would provide better services to Aboriginal women with HIV and their families. What I came to understand through interviews with the women participants is that they are supported, they and helping professionals have been engaging in processes of decolonization. It was clear that the barriers to decolonization and service provision are due to lack of adequate funding for northern programming and services. In addition, there is a lack of curriculum in schools of social work that addresses colonization and the need for de-colonization practices. Lobbying for more funding must continue at the community level as more funding would mean improved services not only for the women that access HIV services in the North but, for the helping professionals supporting these women.

Limitations

I was the only person involved in coding the data and identifying themes from the data with this research project. Transcripts of the interviews were shared with my thesis supervisor and while this process provided consistency in the method used to code data and develop themes, it also limited the perspective of the research. Future studies using this method may consider coding data with the research participants and sharing this with other researchers. Another limitation of the research is that there were not more opportunities for the participants to share about their lives and experiences using other creative mediums. I assume that the research would be richer and more representative of traditional creativity if there were non-textual ways of communication for the participants. This was made difficult in part due to the fact that I moved out of Prince George part way through this research project. Further research projects with similar participants and a focus on creativity would benefit from including visual and oral pieces

of creativity. I was also unable to personally share the completed transcripts and subsequent themes with the participants partly due to geographical distance and partly as a result of not having contact information for the participants. I did, however, leave sealed envelopes for each participant with a draft copy of the thesis and telephone and e-mail contact information for me should they want to discuss the results or clarify any of the content. I was contacted by only one of the participants and she just wanted to verify that her information was correct. Future research projects may consider setting up transcript review meetings at the end of the interviews as this may result in the opportunity to share the transcripts and themes in person.

Future Research

Further areas of study surrounding this topic and/or informed by this research include: further analyzing the colonization and/or decolonization practices of aboriginal and non-aboriginal HIV/AIDS organizations. Additionally, a study looking at the federal and provincial debate over which entity is responsible to transfer funds to the provincial and municipal health organizations and the impact this debate has on service provision to aboriginal women living with HIV/AIDS in Canada. A study focusing on the experiences of HIV positive Aboriginal women when accessing helping services would likely be helpful in illuminating helping professionals' attitudes, and gaps in HIV/AIDS specific education. Additional studies addressing attitudes of family and community members would be beneficial in pinpointing educational and awareness needs for persons affected by HIV/AIDS. Reclamation of voice and vision continue to be areas that can be expanded upon in similar research to encourage participants to continue to engage in the process of decolonization and heal themselves and their communities.

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Appendix A: Consent to Participate

Do you understand that you have been asked to be in a research study?	□ Yes	□ No
Have you read and received a copy of the attached information sheet?	□ Yes	□ No
Do you understand that the research interviews will be recorded?	□ Yes	□ No
Do you understand the benefits and risks involved in participating in this study?	□ Yes	□ No
Have you had an opportunity to ask questions and discuss this study?	□ Yes	□ No
Do you understand that you are free to refuse to participate or to withdraw from the study at any time? *You do not have to give a reason and it will not affect any medical or other kind of care you are receiving.*	□ Yes	□ No
Has the issue of confidentiality been explained to you?	□ Yes	□ No
Do you understand who will have access to the information you provide?	□ Yes	□ No

This study was explained to me by: _____

Print Name

I agree to take part in this study:

_____ Date: _____

Signature of Research Participant

_____

Printed Name of Research Participant

_____ Date: _____

Signature of Witness

_____

Printed Name of Witness

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

_____ Date: _____

Signature of Investigator

APPENDIX B: INTERVIEW QUESTIONS

1. I would like to invite you to tell me your story about being an HIV+ Aboriginal woman in the North. This story may emphasize any aspect of this experience that you like.

2. Has living in the North played a significant part of your experience of dealing with HIV? If so, please explain.

3. What do you perceive to be your strengths in dealing with HIV.Do you think the fact that you are a woman has significantly impacted that experience? If so, how?

4. Can you tell me about how these/this relationship(s) lead to strength, resiliency, and transformation?

5. What do you think that helping professionals (social workers, counselors, can do to support creativity, resilience and strength with aboriginal women who are HIV+?

6. Is there anything else that you feel we may not have covered in this conversation that may be helpful/important?