

ABORIGINAL COMMUNITIES IN CANADA AND HIV/AIDS:  
THE VOICES MUST BE HEARD

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## ABSTRACT

The purpose of this research was to develop a theory grounded in the life experiences of Aboriginal community members in Canada that describes the ways in which they have been affected by HIV/AIDS. This theory has incorporated the effects of colonization within Aboriginal communities; although historical, effects of colonization have been linked by researchers to many health challenges confronting Aboriginal communities today. This thesis has reviewed the research evidence that suggests the higher prevalence and incidence of HIV/AIDS in Aboriginal communities has roots in historical colonization. The qualitative data collected provides experiential information documenting present-day experience of community members who are affected by HIV/AIDS in Canada. I conducted 20 qualitative interviews with Aboriginal community members from across Canada who have been infected (been diagnosed with) or affected (relative has been diagnosed with) by HIV and AIDS to gain a better understanding of how HIV/AIDS is changing the health landscape within Aboriginal communities. Grounded theory methodology was utilized to analyze the interview data. The participants in this research are made up of a unique group of Aboriginal individuals in Canada and may represent the experience of a portion of the population.

As there is a paucity of research about Aboriginal Peoples living with HIV and AIDS in Canada, the results of this research study has contributed to development of a theory describing what it is like for Aboriginal Peoples who are living with or affected by HIV/AIDS and suggestions about culturally relevant methods of healing. This research gave voice to those Aboriginal community members in Canada, who are diagnosed with HIV/AIDS or affected by HIV/AIDS. The theory describes participants' journeys of

transformation where they have learned to embrace their new identities. Life experiences of Aboriginal community members in Canada that were infected by HIV/AIDS (APHAs) or family members affected by having a loved one infected by HIV/AIDS (APAAs) generated a propositional theory. APHAs who participated in the study were significantly open about their identity with HIV/AIDS and most identified with also being affected by HIV. The APHAs were more willing to be open about their diagnosis and were very interested in sharing their life experiences of living with HIV/AIDS. They made up over half of the participants in the study (n=14). Those individuals that were APAA's were more challenging to recruit, and ultimately, I extended my study by another year to ensure that Aboriginal community members who are affected by HIV/AIDS participated. They made up approximately one third of the participants (n=6). The theory suggests that these individuals are more likely to have not shared their life experiences with other

The current propositional theory that emerged suggests that the healing journeys of APHAs and APAAs are significantly different in nature. The tree depicts the emerging theory, *a journey on the path to psychological and cultural healing: transformation of identity*. The visual depiction includes the transformation of identity that an Aboriginal individual might experience when living with their HIV diagnosis or having been affected by HIV either directly or through a loved one being infected. Two models emerged that depict the journey and the transformations of identity that begin as seeds in the earth and throughout the transformation grow into trees.

## ACKNOWLEDGEMENTS

As a First Nations woman, mother, wife and student I have had many challenges to overcome while on my journey within academia. Have also had the privilege to be guided by Elders and assisted me to remain connected to my traditional teachings and having connections to my Aboriginal community. I know if I had not had the support of ceremonies I would not have reached the completion of my dissertation. One of the most significant experiences I have had was engaging in this research with our Aboriginal community members across Canada who are experiencing HIV/AIDS. I am truly grateful to those Aboriginal community members in Canada who shared their life experiences with me. Many people have assisted me by investing their time and knowledge to this dissertation. I extend much respect and thanks to my supervisor, Dr. Mary Hampton who has provided support, guidance and understanding while I navigated on this journey. I would also like to thank the members of my committee Drs. Angelina Baydala, Regan Shercliffe and Jo-Ann Epsikenew for the investment of their time, expertise and support. I would also like to extend my thanks my external examiner Dr. Lynn Lava lee, investment of her time, expertise and support. I would also like to acknowledge the Faculty of Graduate Studies and Research at the University of Regina for providing scholarships to help fund my studies and research. I also received financial support from the National Aboriginal Achievement Foundation (NAAF), Canadian Institute of Health Research (CIHR), Indigenous Peoples Health Research Centre (IPHRC) and Touchwood Post Secondary.

## DEDICATION

I would like to dedicate this dissertation to the twenty Aboriginal individuals who participated in this research. Without them, this research would not have been possible. I would also like to dedicate this work to all Aboriginal peoples in Canada, my family and my extended family. I am also very thankful to my husband, Patrick, my children Raymond, Rowan, Justin, Shay and Isaiah. I have always appreciated their unconditional love, support and encouragement. My family has always encouraged me to continue on with this journey, even if I had to miss a lot of their important days. I know that now that this is done, I will make up for the time we missed. Hiy Hiy! I would also like to acknowledge my husband for the artwork that he created of the models that portray the journey of transformation; together we make a good team. In memory of my good friend and mentor, late Ken Goodwill, who always told me he believed in me. I did complete this journey, and extend many thanks to all who walked with me on this path.

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# 1. INTRODUCTION

## 1.1. Motivation

My motivation for conducting my doctoral dissertation research with my Aboriginal community members in Canada affected by and diagnosed with HIV/AIDS was directly related to my desire to assist in understanding an illness that is at epidemic proportions within our Aboriginal communities across Canada. I set out on this journey with a strong interest in gaining a better understanding of HIV/AIDS and how Aboriginal communities are being affected by seeking western and traditional Aboriginal knowledge about HIV/AIDS. On this journey, I have come to realize that this work has its own purpose and ultimately, this research has its own trajectory that is independent of me. Nonetheless, I am wholly invested personally and professionally in assisting Aboriginal communities to gain knowledge, develop understanding and skills in order to reduce the rates of this illness and its impact on our people.

I have known a number of Aboriginal people with HIV/AIDSs who have joined the spirit world. They taught me many life lessons that I continue to reflect upon today. I have chosen to continue my work in this area because of the passion I feel towards finding ways to assist in this fight, whether it is in academic work or by volunteering my time. I also do this work to honour those who are diagnosed with HIV/AIDSs, have a loved one diagnosed with HIV/AIDSs, those who have passed away and dedicate this research to all Aboriginal communities in Canada. First and foremost, my oldest and wise sister, Sonia Lynn McKay was diagnosed with HIV/AIDS in the late 1980's and left to the Spirit World in 1995 at the age of 30. My honors and Masters theses, which were focused on Aboriginal women, who were HIV positive or affected by HIV/AIDS in Saskatchewan



were dedicated to her. Secondly, around the time I was set to defend my master's Thesis, a friend, mentor and colleague of mine who I worked with on the Board of Directors at All Nations Hope AIDS Network had a tremendous impact on my work. Mr. Tim Laughlin asked me if I was going to continue doing HIV/AIDS research for my doctoral dissertation. At subsequent meetings, he consistently reminded me that while HIV/AIDS was affecting our women, it was also affecting all Aboriginal community members across Canada. His efforts helped me widen the scope to include all Aboriginal community members, as there were also many lessons to be learned, from our men, women, youth, and elders. Tim joined the spirit world in 2006. As a result of his guidance and a great deal of guidance, support and encouragement from many others within my community, this dissertation will focus on our Aboriginal communities across Canada.

My Masters thesis was a qualitative study about Aboriginal women living in Saskatchewan. In my Masters research I gained a better understanding about the emotional experiences that Aboriginal women in Saskatchewan faced in regards to diagnosis, disclosure, coping and if they accessed traditional and cultural supports for HIV/AIDS. The findings of my Masters research provided a propositional theory that suggests that each Aboriginal woman is walking on a path to healing with steps on the medicine wheel that include acceptance, identity, support and risk factors. I identified gaps in my Masters research that required further investigation to determine if other Aboriginal community members in Canada shared similar experiences and if the themes identified in this study may relate to other Aboriginal community members experiences with HIV/AIDS.

The purpose of my Ph.D. research was to gain a better understanding about Aboriginal Peoples in Canada, being inclusive of the life experiences from Aboriginal men and women across Canada. I was interested in further investigation about the gaps that emerged from my Masters research with Aboriginal women, including developing a psychological theory utilizing an Aboriginal cultural lens. In my Ph.D. research I also embarked on a journey to gain a better understanding about what types of interventions and recommendations Aboriginal community members in Canada could suggest as I sought to develop a culturally relevant psychological theory. Further investigation was required to understand the life experiences of Aboriginal individuals in Canada who were diagnosed with HIV/AIDS or who have a loved one diagnosed with HIV/AIDS.

Primarily, the goal of this qualitative research was to generate a culturally relevant theory describing experiences of Aboriginal community members in Canada infected and affected by HIV/AIDS. Ultimately, the hope is for this theory to be utilized to guide development of psychological services for Aboriginal communities as members cope with the effects of HIV and AIDS. Presently, there is a lack of literature that includes Aboriginal voices from Canada in sharing their life experiences. In this dissertation, I present a literature review describing the background on the definition of Aboriginal Peoples Having HIV/AIDs (APHAs). I will also describe the impact of colonization on Aboriginal Peoples' health today; the incidence and prevalence, treatment and gender differences of HIV/AIDs; and cross-cultural psychological literature on HIV/AIDs

As I indicated above, I am a First Nations woman who has been closely affected by HIV and AIDS. When my eldest sister was diagnosed with HIV it was the first time

that our family was directly affected by this disease. Some family members were willing to accept her with unconditional love. Others were not ready at the time and even after she passed away, have continued to deny that she had HIV. They would rather believe that she died of another disease, such as cancer, as they were not prepared to attach the stigma of HIV that exists within Aboriginal communities in Canada to her or the family.

I am greatly indebted to and motivated by those individuals who have shared their life experiences and lessons with me. I continue on this journey to create a better understanding about HIV/AIDS within our Aboriginal communities.

## 1.2 Elders as Leaders.

One of the first steps that I took in my research study was to ask for the assistance of two guiding Elders. Elders have been important resources for Aboriginal communities who are healing from the effects of colonization. Elders are thought of traditionally as being a highly respected older person who holds the knowledge of the ancient wisdom, spiritual and cultural traditions of their people (Hampton et al., 2007; Kulchyski, McCaskill & Newhouse, 1991). Cajete (1994) suggests that Elders act as bridges to spiritual experience and teach others about spiritual knowledge. My two Aboriginal Elders who guided me in my study from the onset to the analysis of data as well as all other steps in the research process. It was important for me to have a gender balance in this guidance and I approached a male and female Elder with respect and traditional protocol. I presented them each with cloth and tobacco and formally asked for their prayers and guidance throughout the entire research process. The male Elder, He Who Chased The Enemy agreed to assist in my study and passed away in September of 2010. He shared much wisdom, respect and guidance throughout our meetings and discussions

about my research study on HIV and AIDS. When I approached him and asked him to assist me with my research, he shared with me that he did not know a lot about the illness, but would certainly provide me with good thoughts and prayers using the tobacco and cloth I provided. He was a great mentor and friend and I will always treasure the lessons he shared. I am a Cree/Saulteaux First Nations woman who has had numerous teachers and mentors. He Who Chased the Enemy was my mentor and out of respect and in memory for him, I did not approach another male Elder to assist with my dissertation. In my culture, we mourn the loss of a person we loved for four years, accompanied by ceremony. I am still grieving the loss and from my teachings, it would be disrespectful to replace an Elder who had provided the prayers and support at the onset of the research. The female Elder has continued to assist me in the process of research as we have journeyed together throughout the past four years. She has provided much mentorship, guidance and support. She has extensive experience within our Aboriginal communities through educating, advocating, and being active in research projects about Aboriginal sexuality and health. Ultimately she has been a great addition to my research. I am truly thankful for her unconditional support throughout our many discussions and meetings about this research. Without the support of these Elders, my journey would have been a much different one. I treasure the support and guidance I have received through their teachings and will be forever grateful.

### 1.3. Definition of Aboriginal Peoples

As the focus of this research is with Aboriginal people across Canada, I have provided a brief summary of some of the important terms. The Aboriginal people of Canada are made up of three distinct groups: First Nations, Métis and Inuit (Department of Justice

Canada, 1982). In 1982, the Canadian constitution defined Aboriginal Peoples as: “Indian”, “Inuit” and “Métis”. To be consistent in this research and given the variety of terms that continue to emerge regarding the First Peoples of Canada, the definition I will utilize to describe participants in this study defines Aboriginal as being made up of First Nations, Métis and Inuit. No other culture in the world continues to have its ethnicity or ancestry labeled by a government, so it is important to emphasize that the Canadian government continues to maintain its control over Aboriginal Peoples by defining who “belongs” and who does not belong to the category Aboriginal Peoples through the definition provided in the Indian Act (Satzewich & Liodakis, 2007; Virtual Law office, on line resource, 2009). The Indian Act has been denounced by many Aboriginal researchers as paternalistic legislation that was created to control every aspect of the lives of status Indians, each of whom is subject to this special legislation (Episkenew, 2009).

The goal of my research was to include participants from all Aboriginal Peoples in Canada (or at least recruit as diverse a sample as possible) in order to gain a better understanding about their experiences with HIV and AIDS. Therefore, in this study, I define Aboriginal as individuals who self-identify as First Nations (status/non-status), Inuit or Métis. A term often used interchangeably with Aboriginal is “Indigenous”, which describes Aboriginal Peoples as the original first peoples or descendants of first peoples to the land who have lived here since “time immemorial”; this term will also be utilized throughout this proposal to describe Aboriginal Peoples (Mihsuah, 2003; Ray, 1996). I have reviewed literature about Native Americans/American Indians in an effort to include experiences of HIV/AIDS, as in the U.S. there have been some studies with Native Americans and HIV/AIDS. In this dissertation I will also use the term Native

Americans/American Indians, which is defined as being a member of the Aboriginal peoples in the western hemisphere (Merriam-Webster, 2005).

#### 1.4 Definition(s) of Two-Spirit/Two-Spirited

At the onset of recognition of HIV/AIDs in North America (in the 70's to the 80's), the majority of the individuals being diagnosed were gay men. The disease was seen as a gay male disease. Within many Aboriginal communities, the definition of the term "gay" was unclear at this time and has gone through several iterations of definitions to clarify their sexual orientation.

In some Aboriginal cultures, men who have sex with men and women who have sex with women can be described as being gay, lesbian and/or two-spirited. Vernon (2001) suggests that two-spirit includes men, women and youth who are gay or lesbian. Literature suggests that within most Aboriginal societies, two-spirited encompasses the combination of masculinity and femininity often attributed to males in a feminine role and females in a masculine role (Gilley, 2006; Vernon, 2001; Lang, 1998). Wilson (2009) defines two-spirit identity as an empowered identity that emerged within the context of sustained racism, homophobia and sexism. She suggests that two-spirited individuals are proclaiming an identity that honours and integrates sexuality, gender, culture, spirituality and all other aspects of who they are (Wilson, 2009).

Researchers and academics over time have developed a number of terms and definitions to portray this diversity within the context of identity and sexuality. Additionally, Indigenous populations are describing their own diversity, developing their identities and definitions of identity within this context. Lang (1998) suggests that within many Indigenous communities, Native American gays and lesbians may identify with the

combination of the masculine and feminine potentials as a connection to their “spiritual” qualities.

For example, anthropologists and other researchers have historically used the term the term *berdache* to identify an individual within a tribe who is held in high esteem such as a medicine person with special powers spiritually, and this would include both male and female genders (Lang, 1998). Vernon (2001) described the term *berdache* as originating in Persia, adopted into the Italian language and appearing in Spain and France around the sixteenth century. Anthropologists used the term *berdache* over the past century to describe homosexual activity among tribal people (Vernon, 2001; Gilley, 2006).

Gilley (2006) described a historical change in terminology that was spearheaded by Indigenous researchers in the mid-1990s. As a whole, the community members decided to take back their definition/symbol of gender diversity that had been appropriated by non-Aboriginal researchers. With this action, many Aboriginal community members and researchers refused to use the colonial derived term *berdache* and proposed the term two-spirited (Gilley, 2006). This term was created by Aboriginal gay community members to encompass an individual’s gender identity. They defined two-spirited as meaning beyond sexual orientation, suggesting an acceptance and recognition of such an individual’s place and role in the community (Vernon, 2001). Gilley suggests that two-spirited identity consists of multiple cultural ideologies including Indianness, whiteness, gayness, straightness, masculinity, femininity and authenticity. His research describes the movement within the gay community to come to terms with an agreed upon definition in regards to Aboriginal two-spirited individuals.

Gilley (2006) suggests that prior to contact, there was sexual and gender diversity, which continues to the present day. More importantly there is the suggestion of a third gender. Researchers suggested that in some historical Aboriginal societies, gender identified two-spirited people were referred to with a third gender term and accepted within their culture. However, anthropologists then labeled this other gender as *Berdache* and it was taken out of context and misappropriated (Roscoe, 1993; Lang, 1998; Gilley, 2006).

The topic of “gender” has been debated for a long time. The definition of gender identity occurs as a psychological sense of oneself as a female or male (Unger & Crawford, 1996). Garnets (2002) suggests identifying a better framework for thinking about gender related issues, as there is currently disagreement in the literature about terminology in regards to gender. She suggests that it is important to examine how other cultures have incorporated gender and sexual diversity into their traditions and cultures. For example, she compared Native American and Euro American notions of sexuality and gender highlighting research conducted by Terry Tafoya (Garnets, 2002). Tafoya (1997) reported that of the approximately 250 Native languages still spoken in the United States, approximately 168 have terms for people who are not considered male or female. Sexual orientation conceptualizations may also be less based on linear ways of reasoning, which are typical of Western thinking, and more on circular ways of thinking, more typical of Aboriginal ways of knowing. As such, theoretically, an infinite number of possible points of sexual identity may exist, in these non-Western cultures. He proposes that this serves as an excellent example of the ways in which other cultures can provide



models of diversity that may prove more useful than the dominant Western models (Tafoya, 1997).

### 1.5 Definition of Aboriginal Peoples having HIV/AIDS

Through medical advancement, HIV/AIDS is no longer a death sentence but rather a chronic illness that can be managed through medical treatment (Gahagan & Loppie, 2001; McKay-McNabb, 2005). Over the past few decades, new terms have been developed to assist those involved in providing care to Aboriginal peoples diagnosed and living with HIV/AIDS (Aboriginal Nurses of Canada, 2001; Canadian Aboriginal AIDS Network, 2002; McKay-McNabb, 2005). For example, the Canadian Aboriginal AIDS Network (CAAN, 2000; 2002), The Red Road HIV/AIDS Society (2000), The Public Health Agency of Canada (PHAC) (2008) and All Nations Hope AIDS Network (2001) have defined an Aboriginal Person living with HIV/AIDS as an APHA. As the terminology evolved from within communities, it generated dialogue, as well as written materials and research, which has ultimately resulted in specific definitions of APHAs. That is, the definitions (i.e., APHA) are unique to those Aboriginal individuals who identify as people who are “living with” rather than “dying from” HIV. The definition for an Aboriginal Person Affected by HIV/AIDS (i.e. APAA) is defined in this research as someone who has a loved one (e.g. relative, extended family, friend) diagnosed with HIV/AIDS.

In the following review, I will explore the life experiences of Aboriginal community members in Canada who are diagnosed with and/or affected by HIV/AIDS. This research study emerged from the growing evidence that HIV and AIDS has disproportionately affected Aboriginal communities in Canada, yet few researchers have

directly asked community members about their experience. I will include a review of the literature that describes the impact of colonization on Canadian Aboriginal Peoples' health today, the incidence and prevalence, treatment and gender differences of HIV and AIDS, and cross-cultural psychological literature on HIV and AIDS. Finally, I will consider how these influences have directly affected Aboriginal community members in Canada by sharing stories of their life experiences of HIV and AIDS.

## 2. LITERATURE REVIEW

### 2.1 Brief History of Aboriginal Peoples and the Effects of Colonization

Throughout history, numerous Aboriginal Peoples have been deeply affected by colonization, and they continue to be disproportionately affected today relative to other Indigenous populations throughout the world. Canada is the only country in the world where the government defines who an Aboriginal person is. Colonization has been described as an attempt to erase the roots and destroy the traditions of many Aboriginal Peoples (Anderson, 2000; Bourassa, McKay-McNabb & Hampton, 2006; Hampton, McKay-McNabb, Farrell Racette & Byrd, 2007; Absolon & Willett, 2005; Fournier & Crey, 1997). Historians suggest that when contact between Europeans and Indigenous Peoples occurred in North America, Europeans imposed a new way of life which resulted in devastating effects to many Aboriginal Peoples, including but not limited to a change in their communal living; effects also included exposure to new diseases for which many Aboriginal Peoples did not have resistance or immunity (Waldram, Herring & Kue Young, 2006; McLeod, 2001; Hanson & Hampton, 2000). Many generations of Aboriginal Peoples died from the new diseases brought over by the Europeans and the population depleted drastically (Waldram, Herring & Kue Young, 2006; McLeod, 2001). The mortality rate was high for many Aboriginal Peoples following contact and continues to be higher than for non-Aboriginal People in Canada

Researchers indicate that current and historical literature inaccurately reflects the reality of many Aboriginal Peoples since history has been portrayed through the lens of the “conqueror” or the non-Aboriginal Peoples who have written the history (Anderson, 2000; Episkenew, 2009; Absolon & Willett, 2005). For example, numerous Aboriginal

Peoples were not recognized by the newcomers of North America (Europeans) as a people and as being a part of society. They were considered to have a less than value than the newcomers, which resulted in colonizers believing they had the right to take over the land from the Indigenous inhabitants in order to settle (Anderson, 2000; Episkenew, 2009; Chrisjohn & Young, 1997).

Colonization resulted in numerous challenges, including a disconnection of numerous Aboriginal Peoples from their natural being and context (Anderson, 2000; Hampton et al., 2007; Absolon & Willett, 2005; Farrell Racette, 2001; Hanson & Hampton, 2000). Colonization also resulted in a triangle of power where the people at the top claimed they have the right to control people at the bottom (Episkenew, 2009; Bourassa et al., 2006; Yazzie, 2000). Almost all academic curricula presented in Canadian universities and colleges supports Eurocentric worldview. As a result, Canadians' worldview and information systems perpetuate the dominant Eurocentric knowledge base and context and ignore Aboriginal worldviews, knowledge and thought (Youngblood Henderson, 2000). Furthermore, although, in some cases, numerous Aboriginal Peoples kept a record of their history through oral traditions, they were and are to this day, a culture that passes on knowledge through oral tradition (Hampton et al., 2007; Moodley, 2005; Dickason, 2002; Garrett & Herring, 2001).

History was also rewritten when describing Aboriginal Peoples' health and lifestyle. For example, anthropologists in 1930 suggested that many Plains Aboriginal Peoples lived a precarious migratory existence, experiencing accidents, having frequent famines, and experiencing many conflicts within and between nations (Waldrum, Herring & Young, 2006). However, historians today disagree with the descriptions presented by

anthropologists who wrote about Aboriginal Peoples in 1930. Today, contemporary Indigenous historians describe most Aboriginal Peoples as having the ability to survive since time immemorial (McCleod, 2001). Numerous Aboriginal Peoples were able to survive in harsh conditions on the land when the Europeans were perishing in the winters when they arrived. Furthermore, many Aboriginal Peoples continue to be successful hunters and gatherers with the ability to obtain stable supplies of food for their tribes and brave the elements of the weather. They were in significantly better health prior to contact due to use of their traditional medicines and reliance on community healing ceremonies (Waldram, Herring & Young, 2006). The implications of the “rewriting of history” are that I cannot rely on written documents to portray an accurate description of Aboriginal Peoples’ health and wellbeing.

Other factors that influence health of numerous Aboriginal communities today are a combination of discriminatory experiences that have been referred to as “multiple oppressions” (Bourassa, 2008). Previous researchers have found that race, culture, gender and ethnicity are important determinants of health and are often interrelated (Waldram, Herring & Kue Young, 2006; Bourassa et al., 2006; Armaratunga, 2002). Aboriginal and non-Aboriginal scholars agree that the HIV epidemic among most Aboriginal peoples in North America is fundamentally linked to the cumulative impact of colonization (CAAN, 2011). In analyzing the data collected for this thesis, I took into consideration the concept of “multiple oppressions” when developing an understanding of participants’ life experiences.

The policies developed by the Canadian government are connected to the experience of “multiple oppressions”; these policies are based on a belief that numerous

Aboriginal Peoples were incapable of looking after themselves, even though they had done so for thousands of years before the arrival of the European fur traders and the settlers. Europeans were biased in their views of the new world and truly believed that European societies were the epitome of all societies. Major problems with policies legislated by the Canadian government resulted from the Indian Act. Specifically, those policies did not respect or recognize the existing culture of many Aboriginal Peoples. The Europeans believed that they were superior and were more evolved than most of the Aboriginal Peoples. As well, most Europeans believed that the Aboriginal way was unsustainable and “barbarian.” An example of the government policy is reflected in a statement made in 1920. Duncan Campbell Scott, the Deputy Superintendent-General of the department of Indian Affairs described stated that “Our objective is to continue until there is not a single Indian in Canada that has not been absorbed into the body politic and there is no question and no Indian department” (Ponting, 1989, pg. 26).

The Indian Act (passed in 1876) defined Indian identity. Lawrence (2000) suggests that the social construction of “Aboriginal” imposed by the Indian Act legislation influenced many Aboriginal people to think about all things “Indian” in a negative way. The psychological impact of this imposition on many Aboriginal Peoples was development of an internalized sense of inferiority (Anderson, 2000; Bourassa, et al., 2006). Furthermore, the Indian Act has controlled and defined Aboriginal identity by creating legal and non-legal categories for membership conveying rights and privileges for members both within and beyond many Aboriginal communities (Bourassa et al., 2006; Lawrence, 2000).

An example of a policy that has resulted in inter-generational psychological and physical distress is the residential school policy. From the early nineteenth hundreds to as recent as 1990s, status/non-status, Metis and Inuit children were required to attend Indian residential schools (Episkenew, 2009; Barlow, 2005; Hanson & Hampton, 2000; Anderson, 2000; Brasfield, 2001; Fournier & Crey, 1997; Chrisjohn & Young, 1997; Miller, 1996). This policy, regulated by the Indian Act, was enforced across Canada by the Royal Canadian Mounted Police and Indian agents (Episkenew, 2009). The majority of Indian agents were non-Aboriginal federal employees who were positioned on reservations and reserves to be the eyes and ears for the government; many Aboriginal individuals or families could do nothing without direct permission from the Indian agent on reserve. For example, if a child was considered ready for school, the Indian agent facilitated the act of removing the child from their family and having him/her sent to residential school. Children as young as 3 years old were taken from their homes and family; they grew up institutionalized (Hanson & Hampton, 2000; I. McNab, personal communication, March 9<sup>th</sup>, 2006). Attendance at these schools resulted in children who were forced to sever ties with family members who could have nurtured these children and given them the love and guidance that their parents wanted to give (Episkenew, 2009; Anderson, 2000; Hanson & Hampton, 2000; Fournier & Crey, 1997; Chrisjohn & Young, 1997; Miller, 1996). The majority of status Indian children was not given a choice and were not raised and nurtured by their parents, which resulted in detrimental psychological and physical effects on generations of numerous status Indians in Canada (Hanson & Hampton, 2000; Miller 1996).

The issue of “identity” is an important consideration when developing a theory in this research since many researchers suggests that colonization is strongly linked to identity and subsequently to health problems affecting most Aboriginal communities (Episkenew, 2009; Bourassa, 2008; Bourassa et al., 2006; McKay-McNabb, 2005). The construction of Aboriginal identity that would naturally develop within the context of Aboriginal families was interrupted when the Canadian government defined who is and who is not Aboriginal; the policy that resulted in residential schools was an effort to “take the Indian out of the Indian” (Anderson, 2000). Currently, there continue to be debates about the social and legal definitions in the labeling of many Aboriginal Peoples in Canada (Episkenew, 2009; Satzewich & Liodakis, 2007; Bourassa, 2008; Bourassa et al., 2006). The issue of “identity” and the link between assimilationist policies (i.e., colonization) and ill health of numerous Aboriginal individuals, their families and communities has been identified by researchers (Episkenew, 2009; Bourassa, 2008; Bourassa et al., 2006). Bill C-31 was an amendment to the Indian Act to be in line with the Charter of Rights and Freedoms. Specifically, three principals guided the amendments to remove gender discrimination, restore status and membership rights as well as increase band control over their own affairs (INAC,1995). Recently, the McIvor decision resulted in an effort to acknowledge gender discrimination to Indian registration (INAC, 2010). Ultimately, these decisions have had numerous ramifications and are a step in the right direction for equality.

The Indian Act also reinforced a sexist specification (Anderson, 2000; Bourassa et al., 2006; Lawrence, 2000). Specifically, the ramifications of the Indian Act were more severe for Aboriginal women than men. For example, when a status woman married a



non-status man, according to the act, she lost her status. However, if a status man married a non-status woman, she gained status and so did her children, even if they were not the status man's children. These problems continue to have a negative impact on numerous Aboriginal women and community members today (Anderson, 2000; Bourassa et al., 2006).

#### 2.1.1. Distinction Between North American Indians and Canadian Aboriginal Indians

Vernon (2001) described in Native American communities in the United States historically there have been numerous problems in meeting the basic needs for health care. From 1920 to 1950, the Bureau of Indian Affairs was in charge of the health care for Native Americans, which resulted in serious health disparities between Native Americans and Americans. Following this, there was a move within the U.S. Government to another department because of the historical health disparities and inadequacies that were affecting the overall health of most Native Americans (Vernon, 2001). In the 1950's, the move from the Bureau of Indian Affairs to the United States Department of Health, Education and Welfare proved to result in slight improvements to health of this population; providing limited services on reserve and in urban settings. In Canada, historically health care for on-reserve treaty status Indians was limited and the majority of health care was located on reserves. Historically, urban health care supports for off reserve status Indians are limited, resulting in next to nothing for health care supports. In some cases, on reserve health care included the 'medicine chest'. Health care was an addition added to treaty six for health care that was created when treaties were signed across Canada. If a reserve was a part of the treaty area that included health care, they did

have access to very limited health care services. In contrast, if a Métis person required health care in Canada, they did not receive any support for their health care needs. Health care disparities between groups of Aboriginal peoples have resulted in Canada since adoption of the Indian Act. It is apparent from the limited health care services and supports that both diverse populations face barriers in regards to their health care coverage, services and supports.

There are distinct differences between Native Americans and Aboriginal Canadians and their experiences of HIV and AIDs. Specifically, most Native Americans have extensive experience in regards to HIV/AIDS and have developed nationwide supports and services in regards to HIV and AIDS for over forty years (Vernon, 2001). In Canada, we have only recently begun to have a National presence for supports for most Aboriginal communities in Canada and HIV/AIDs (CAAN, 2002). Numerous Native Americans may access Indian Health Services to meet their health care needs (Vernon, 2001). In Canada, the majority of the Aboriginal population has limitations on health care in terms of access and resources have been reduced over time. Specifically, if a person is considered under the Indian Act to have status, they may have access to more health supports than a Métis individual who cannot access health supports. According to INAC (1999):

Knowing which programs and policies apply to you may be difficult. Social legislation varies across the ten provinces and three territories and so do the services available to Canadians in general and to Aboriginal people in particular. What you are eligible for depends largely on where you live.

Most importantly, health care supports and services for most Aboriginal individuals with HIV/AIDS are almost non-existent in today's society due to constant revisions to Health Care Services provided by INAC.

My moshum (grandfather) shared a story with me when he described how he and his twin brother came to Canada. He described fleeing for their life, as at that time, in the 1930, Native Americans were being “run out of the country.” He and my mooshum’s twin brother, at the age of ten, were given the responsibility to carry on the traditions, spirituality and the legacy of the family. They were sent from Montana to survive in Canada. They traveled for many months and arrived in the vicinity of Cowessess and Sakimay First Nations. This is where they ended up after many months of traveling and struggling for their lives. They knew that they would never see their family members again. They grew up without ever knowing what happened to their parents and they died in Canada without returning to their traditional territories in the United States. When they arrived, they were welcomed into the community and eventually adopted, accepted and added to the “band list.”

My moshum Marvin’s stories made me realize at a young age that Aboriginal/Native peoples from the U.S. and Canada were different in many ways. Specifically, the governments at the time were dealing with Indigenous populations in very different ways. The Canadian government wanted to assimilate Indians, and the U.S. were focused on removing Indians from the land, even if that included physical force and resulted in death of Indian people. My moshum stated that if he had stayed with his brothers back in the U.S., likely he would not have survived. He learned from others who fled the U.S. that many had died.

#### 2.1.2. Trauma.

The issue of “trauma” in Canadian Aboriginal communities is important to understand since many researchers have linked the previous issues of residential school

policies, identity, and ill health together with resulting psychological and physical trauma. Brave Heart (2007) describes historical trauma as cumulative, resulting in emotional and psychological wounding over the life span of most Aboriginal individuals, resulting in a generational effect. Historical trauma has been strongly associated with colonization in numerous Aboriginal individuals and communities (Robertson, 2006; Barlow, 2003). This historical trauma can be directly related to the health disparities that are affecting the majority of the Aboriginal population in Canada today (CAAN, 2008; Barlow, 2003). Spittal (2007) indicates that a rapid increase in the rates of HIV among most Aboriginal youth is a reflection of the complex effects of addiction, social dislocation, discrimination, human right violations and poverty, all resulting from historical trauma and colonization. This historical trauma has affected numerous generations of Aboriginal people and studies indicate that most Aboriginal people in Canada are disproportionately affected by social/mental conditions related to trauma such as poverty, traumatic injury, suicide, and other mental health and emotional health concerns (Adelson, 2005). The historical intergenerational trauma that many Aboriginal Peoples endured through attendance to Indian residential schools has also resulted in a fragmented sense of identity (Barlow, 2003; Lavallee, 2006; Anderson, 2000).

Residential schools have continued to have a negative impact on numerous Aboriginal community members today. Multiple generations of Aboriginal children were forced by government policy-makers to attend Indian residential schools; they were taken away from their families for the duration of their childhoods. It is unfortunate that there were no efforts made to rebuild communities once they were damaged. Over the past few decades there has been a societal effort to educate other Canadians about the effects of

residential schools. Recently the federal government provided an apology for the generations of children who were forced to attend residential schools across Canada. The apology by the Prime Minister in June 2008 was not well received by many Aboriginal communities. He described the two objectives that the residential school system had as being: 1) to remove and isolate children from the influence of their homes, families, traditions and cultures; and 2) to assimilate them into the dominant culture (Canadian Broadcasting Corporation, 2008). These were objectives based on the view that numerous Aboriginal communities were inferior and unequal to members of the dominant culture (e.g., Euro-Canadians); removal of most Aboriginal children from their homes resulted in loss of their culture and spiritual beliefs. One of the most tragic results was the process of “killing the Indian in the child” (CBC, 2008). Researchers have stated that it will take many generations to heal from this legacy of loss and the impact it had while deteriorating the culture, language and traditions (Wesley-Esquimaux & Smolewski, 2004).

### 2.1.3. Residential Schools.

Since the residential school policy and experience has been identified as having such a severely negative effect on numerous Aboriginal Peoples today, I will review the literature that reveals the link between residential school and disproportionate ill health among most Aboriginal communities today. One of the legacies of the residential schools is the resultant negative emotional, mental, and social conditions that resulted from multiple abuses, poverty and discrimination that many Aboriginal people faced while attending these institutions in Canada (Jackson & Reimer, 2008; Barlow, 2003). Söchting, Corrado, Cohen, Ley and Brasfield, (2007) suggest that these schools had an

explicit policy of assimilation to prevent children from learning their traditional culture and lifestyles. For example, Kirkmeyer, Tait and Simpson (2009) described the impact of The Davin Report (1879) on Aboriginal communities. They indicated that the report recommended a policy of “aggressive assimilation” and described adult Aboriginal community members and Elders as being ‘helpless with the mind of a child’. The report recommended that all Aboriginal individuals be integrated (assimilated) into the emerging Canadian nation state. Aboriginal children were to be separated from their parents and ‘civilized’ through a program of education that would make them talk, think, and act like mature British Canadians (Kirkmeyer et al, 2009). Kirkmeyer and colleagues (2009) indicated that these recommendations necessarily meant elimination of First Nations.

Barlow (2003) described physical and sexual abuses experienced by children who attended residential schools. He stated that not all Residential School Survivors (RSS) were victims of abuse, but they still experienced trauma. He stated that some of the RSS’s experienced vicarious trauma from witnessing and hearing about abuse suffered by children they were close to, and this left them feeling powerless, frightened, because they could not do anything about it (Barlow, 2003). Furthermore, those who did experience sexual abuse while in residential schools have a number of emotional challenges that may include depression, poor self-esteem, sexual dysfunction, promiscuity, alcoholism/substance abuse and an extremely poor sense of boundaries (Crowder, 1995). Emotional challenges linked to the impact of the abuses that numerous Aboriginal children experienced while in residential school are likely key contributors to

the significant spread and rise of HIV/AIDs amongst most Aboriginal populations in Canada.

## 2.2. Colonization and the Shift in Gender Roles

In some Aboriginal societies in Canada, there is an on-going fragmentation of women's roles. Anderson (2000) describes how colonization altered the distinctive way of life for many Aboriginal Peoples in Canada. She further suggests that numerous Aboriginal cultures promoted womanhood as a sacred identity that existed within a complex system of societal relations that were based on balance between female and males. The shift from the original gender balance enacted in traditional roles for women and men changed to many of today's Aboriginal societies enacting the more European "traditional" gender roles. These shifts have resulted in drastic changes in women's roles compared to their ancestors' honoured and respected roles (Bourassa et al., 2006; Lawrence, 2000; Gerrard & Javed, 1998). Prior to colonization, women were often honoured and respected as the matriarchs of the community.

The report prepared by the Royal Commission of Aboriginal Peoples (RCAP, 1996) documented testimony by Aboriginal people from across Canada. This report allowed for a better understanding of issues numerous Aboriginal people face today and documents traditional knowledge (RCAP, 1996). The findings in this report suggest that many Aboriginal women's lives have changed since contact, which has resulted in seriously limiting women's influence in political and social decision making in Aboriginal communities. Prior to contact, Aboriginal women's roles varied from nation to nation, but overall, they were actively included in the politics of community by participating in decision-making, and guiding social relations and family affairs (RCAP,

1996). Prior to contact, Aboriginal women's roles are reported to vary from nation to nation, but overall women were actively included in the political arenas of the community by participating in decision-making, and guiding social relations and family affairs (Anderson, 2000; Lawrence, 2000; RCAP, 1996). In some Nations, Aboriginal women did not have as much influence as in other Nations, but they were still considered to have an essential role in their community because of their skills and knowledge (Anderson, 2000). Evidence suggests that the loss of respect for some Aboriginal women has contributed to their becoming the largest growing segment of Canadian population that has become vulnerable to HIV/AIDS (CAAN, 2002; PHAC, 2007) (further discussed in the final chapter of my thesis).

Other researchers suggest that colonization has resulted in a shift in numerous Aboriginal communities' worldview from a "collectivist" to an "individualistic" one. For example, Rhea (1997) describes most Aboriginal Peoples as having a collective consciousness prior to contact where there was a shared sense of experience and identity among communities, despite tribal (national) differences. McLeod (2001) describes most Aboriginal people in the Plains Cree territory (i.e., central and northern Saskatchewan) having a historical and collective sense of identity. He indicated that the majority of Aboriginal Peoples have been subjected to images in films and ideas of mainstream society that have robbed the Peoples of this collective sense of identity (McLeod, 2001). Overall, the effects of colonization were detrimental to the formation of identity within many Aboriginal population; these detrimental effects still negatively influence the health of many Aboriginal Peoples today (Bourassa, 2008; Dunbar Jr., 2008; Bourassa et al., 2006; Chrisjohn, et al., 2007; Absolon & Willett, 2005).



In summary, contemporary effects of colonization resulted in most Aboriginal Peoples experiencing identity confusion. One reason for this is the Canadian government's attempts to erase their traditions, culture and roots. The traditional practices of passing down information orally through generations were disrupted when Aboriginal peoples were forced to attend residential school and their traditional languages were not allowed to be spoken. This resulted in loss of languages, traditions and oral histories, where these foundational knowledge bases were disrupted, preventing Aboriginal Peoples to believe in them and build a sense of identity (Anderson 2000; Anderson & Lawrence, 2003). This process of erasing numerous Aboriginal Peoples' traditions and identity has been declared an act of genocide and has resulted in many Aboriginal Peoples needing to work hard to recover all that they can to assist in building a strong and positive sense of identity (Episkenew, 2009; Bourassa, 2008; Dunbar Jr., 2008; Bourassa et al., 2006; Chrisjohn, et al., 2007; Absolon & Willett, 2005).

The multiple lenses that researchers have looked through at numerous Aboriginal Peoples have resulted in research that fragments the identities of many Aboriginal Peoples. It is because of this misrepresentation that Indigenous researchers today are committed to recovering the stories, songs, histories, experiences, ancestors, traditions and cultural identities (Hanson & Hampton, 2000; Hampton et al., 2007; Absolon & Willett, 2005; McKay-McNabb, 2005). The results of the Canadian government's "labelling" has had a damaging impact on the identity of numerous Aboriginal Peoples and has left generations of Aboriginal Peoples without a sense of "identity" as an Aboriginal person (Bourassa et al., 2006; Green, 2000; Lawrence, 1999). Policies and laws from foreign governments (i.e., Europeans) shaped the identities of many Aboriginal

people and, in particular, numerous Aboriginal women today (Bourassa et al., 2006; Absolon & Willett, 2005; Anderson, 2000).

### 2.3. HIV/AIDS and Aboriginal Peoples

#### 2.3.1. Definition of HIV/AIDS.

The focus of this research is HIV and AIDS, so I will present information on this disease to set the context. The human immunodeficiency virus (HIV) is the virus that causes Acquired Immunodeficiency Syndrome (AIDS) (Health Canada 1999). The virus attacks specific lymphocytes called T helper cells (also known as T-cells), takes them over, and then the virus multiplies in the host body. This process destroys more T-cells, which damages the body's ability to fight off invading germs and disease (National Institute of Allergy and Infectious Diseases, 2007). When someone is diagnosed as “HIV positive,” it means that the presence of HIV antibodies has been detected in their blood. The main routes of HIV transmission include specific sexual activities such as unprotected anal and vaginal intercourse, injection drug use by sharing used or unclean needles or syringes; and mother to child transmission, in the uterus, during childbirth or through breastfeeding. AIDS, a progressive symptom of HIV, is a syndrome characterized by specific symptoms and/or diseases. The time between initial infection with HIV and the development of AIDS can be ten years or more. New treatments have increased the life span of people living with HIV/AIDS and improved their quality of life (Health Canada, 1999).

#### 2.4. Brief History of HIV/AIDS.

The first identified case of AIDS in North America was documented in the United States in 1981. Initially, it was believed that AIDS was a gay man's disease since it was

first diagnosed in gay men (Farmer, Connors & Simmons, 1996). Women were not thought to be at risk for HIV and AIDS, and were more likely to be overlooked by physicians when symptoms were present. However, many women were diagnosed with AIDS shortly after men were diagnosed in 1981 (Farmer et al., 1996; Stine 1996). Since 1981, the incidence of HIV/AIDS has grown at an alarming rate and has now been labelled a global "epidemic" (Stine 1996). The term epidemic is defined as a disease affecting many persons at the same time, spreading from person to person, and is extremely widespread (Public Health Agency of Canada, 2010). Today young people of all sexual orientations are infected in great numbers (Vernon, 2001). Heterosexual women are being affected by the disease at epidemic proportions (Smith, 2000). However, Validisseri (2003) indicated that the disease is again on the rise in gay communities where 14% of the new cases of HIV are occurring with homosexuals (Halkins, Wolitski & Gomez, 2005).

The etiology of HIV/AIDS has been in debate since the beginning of the epidemic in the 80 (Parker, 2002). Kanabus & Allen (2004) indicate that it is now generally accepted among researchers across disciplines that HIV originally stemmed from the Simian (monkey) immunodeficiency virus. This virus closely resembles human HIV. However, researchers conclude that we may never know exactly where and when the first virus emerged. What is clear is that sometime in the middle of the 20<sup>th</sup> century, HIV infection in humans developed into the epidemic of disease that we now refer to as AIDS. This HIV and AIDS virus has now become an epidemic in many countries and Aboriginal people in Canada appear to be one cultural group that has been affected more than any other cultural group (CAAN, 2005).

## 2.5 HIV/AIDS & Aboriginal Peoples

Currently, national estimates of HIV prevalence and incidence reported for Canada in 2010 (PHAC) suggest that Aboriginal people continue to be overrepresented in Canada's HIV epidemic. This disproportion ultimately increases Aboriginal people's vulnerability to the HIV infection (CAAN, 2006; Public Health Agency of Canada, 2007; Lavallee, 2006; CAAN, 2000, 2005, 2008; Goldston, Albert, Churchill, Schilder, Perry, Makowski, Hogg & McLeod; 2000; Cooper, Maar & Peltier, 2000). Specifically, Aboriginal communities face a great number of new HIV infections each month compared to the non-Aboriginal populations, where new infections are levelling off (CAAN, 2008).

The Public Health Agency of Canada (PHAC, 2007) reported that Aboriginal Peoples make up 3.3% of the population, but approximately 3,600 to 5,100 Aboriginal individuals were living with HIV in 2005. More striking are reports that indicate that Aboriginal Peoples make up 2.8% times higher the overall infection rate compared to the non-Aboriginal Peoples (PHAC, 2007). However, these reports may not present an accurate picture of the actual numbers of Aboriginal Peoples living with HIV/AIDS, as not all provinces (Ontario and Quebec) in Canada record the ethnicity of people diagnosed with HIV and AIDS (PHAC, 2010). Data describing ethnicity are not collected across all provincial and territorial jurisdictions, and our estimates do not accurately portray the actual numbers of individuals affected with HIV. As well the provinces have limited resources for collecting this information. This may also explain why presently there are no clear numbers about the current status and trends of HIV infection and related risk behaviours among Aboriginal persons, so it is clear that additional data

sources are required to accurately understand prevalence. Maitation (2000) reported that AIDS cases are younger in the Aboriginal population than in the non-Aboriginal population. From the current statistics, the Aboriginal populations likely have higher rates than what is known and published.

In 2008, Aboriginal people made up an estimated 4,300 to 6,100 living with HIV. This was an increase of 24% from the 2005 estimate of 3,500 to 4,900 of all infections in 2005 (2010, PHAC). However, these statistics do not portray the full picture of how Aboriginal communities are being affected, as not all provinces report ethnicity. The actual cases are yet to be known, and the actual picture remains to be seen. Most importantly, the prevalence and incidence rates indicate that within Aboriginal communities, the epidemic continues to rage (PHAC, 2010). Time is of the essence and we need to gain a full picture of just how and why Aboriginal communities are being disproportionately affected. Current data does not accurately reflect the actual numbers of individuals who have been diagnosed with HIV. We currently rely on estimates to understand the reasons why Aboriginal communities continue to be significantly impacted by this epidemic. The profound impact of HIV nationally in Canada reveals that Aboriginal peoples in Canada are many more times more likely to be diagnosed with HIV compared to the non-Aboriginal population across all age groups and among both sexes (Ogunnaike-Cooke, Havelson & Archibald, 2011).

## 2.6. Gender Differences and HIV/AIDS

### 2.6.1. HIV/AIDS and Aboriginal Women

When examining HIV/AIDS issues among Aboriginal Peoples in Canada, gender has played a significant role. Researchers have found that Aboriginal women are infected

at higher rates than Aboriginal men (CAAN, 2008; PHAC, 2007; PHAC, 2010). Specifically, between 1998 and 2008, females newly infected with HIV ranged from 43.0 % to 52.8 % of new cases. In 2005, 56.6% of cases diagnosed were women (PHAC, 2010). This overrepresentation of women diagnosed among Aboriginal Peoples has also been attributed to colonization (Simoni, Sehgal & Walters, 2004; Wesley-Equimaux & Smolwowski, 2004). In most Western or patriarchal societies, gender roles are characterized by an unequal balance of power between men and women where women have fewer rights than men (Baksh-Soodeen & Johnson, 2002; Ship & Norton, 2009).

Their roles as caretakers and leaders in their communities have devolved to reflect European gender roles of inequality, where women are expected to be unequal to men (Ship & Norton, 2009; 2001; CAAN, 2007; Bourassa et al., 2006). Gender differences in survival and mortality may also be due to the many responsibilities of women as mothers and caregivers (Ship & Norton, 2009; DeMarco & Johnsen, 2003). Often, women will put the needs of others before their own, which results in women being diagnosed at later stages of HIV and AIDS. Since European contact, the “traditional” (traditional to First Nations) gender roles of Aboriginal women have been altered. This change in gender roles has implications for the higher incidence of HIV and AIDS infection among Aboriginal women and ultimately results in a gender imbalance for this illness.

Currently, young Aboriginal women constitute the largest proportion of Aboriginal HIV/AIDS cases (PHAC, 2010; Ship & Norton, 2009). Available statistics on the disease may not indicate the actual number of infected Aboriginal women as many cases go unreported in the Aboriginal population (Mill, 2000; PHAC, 2010).

Researchers estimate that 25% of HIV pregnant Aboriginal women will transmit the virus to their infants during pregnancy or birth (PHAC, 2010). Birse, Shokoples and Houston (1999) conducted a study of all paediatric centres across Canada from 1995 to 1997. These statistics suggest that 19% of the women in their study were Aboriginal, which suggest that current statistics about Aboriginal women living with HIV may be giving birth at higher rates than non-Aboriginal women.

Craib and colleagues (2003) sought to identify the ways in which Aboriginal women were being exposed to and infected by HIV/AIDS. Aboriginal females constituted approximately 40% of the participants in their study. Craib et al. (2003) found that half of the Aboriginal women became infected with HIV through injection drug use (IDU). Craib et al. (2003) suggested that sex-related and drug-related vulnerabilities facing IDU Aboriginal women may be markedly different than those encountered by Aboriginal men. Particularly, when they compared the rates of new diagnosis of HIV, the researchers suggested that the Aboriginal women were more at risk, due to their involvement with the sex trade and IDU, than men. Merhabi, Peterson, Pearce, Patal, Craib, Moniruzzaman, Schechter and Spittal (2008) identified that young Aboriginal women were three times more likely than men to be HIV positive in a study in British Columbia. They investigated gender differences among Aboriginal peoples who inject drugs in Prince George and Vancouver. Their findings suggest historical trauma and effects of the sixties scoop as some reasons for the increased infection rates for the young Aboriginal women who injected drugs and those who did not. Additionally, Merhabi and colleagues (2008) highlights increased heterosexual acquired HIV among young Aboriginal women.

Further studies are required to gain a better understanding about how Aboriginal women are impacted from colonization to provide a clearer picture of the impact that HIV and AIDS has within the Aboriginal population, and specifically with Aboriginal women. Currently, barriers continue to exist in regards to access to effective health care services and supports for Aboriginal women who are living as a APHA or will be infected by the virus (Ship & Norton, 2009).

#### 2.6.2. HIV/AIDS and Aboriginal Men

Historically, Aboriginal men have also faced significant oppression for being Aboriginal as well as being homosexual from within their own Indian communities (Gilley, 2006). In the late 80's and early 90's, the Gay American Indian (GAI) movement in the U.S. sought to focus efforts on their group's unique health needs. Specifically, the GAI indicated that the U.S. government did not take their health care needs seriously. Furthermore, they felt that the AIDS program overlooked important cultural differences and failed to reach many Indian people. Through their efforts, the group's unique needs were being brought to light and emphasis was then placed on the individual's racial identity(s). Gilley (2006) suggested that Aboriginal men began to integrate the historical knowledge about being two-spirited, as a kind of personhood that was respected and directly related to their cultural heritage. They identified that the health care needs of Aboriginal gay men were unique, and this was the start of movements across North America to advocate for gay and two-spirited individuals.

HIV is infecting both heterosexual and two-spirited or gay Aboriginal men significantly. In 1999, in an estimate of those living with HIV infection, 23% were Aboriginal men who were having sex with men and 6% of cases were Aboriginal men



who were having sex with men and using injection drugs (CAAN, 2001). Although this number is an estimate, it provides some information on how Aboriginal men are currently being affected by HIV at rates disproportionately higher than other cultural groups in Canada. Researchers suggest that males involved in the sex-trade in Vancouver's lower-east side have higher levels of HIV infection and injection drug use, which increases their risk of exposure (Kuyper et al., 2004). In addition, heterosexual Aboriginal men who have tested positive for HIV are becoming fathers (PHAC, 2010). They are in relationships with women with are not APHA and they want to start families. This is a common occurrence in Canada, as more heterosexual Aboriginal men who are HIV positive start to have families.

### 2.6.3. HIV/AIDS and Aboriginal Youth

Historically, Aboriginal youth have been infected with HIV at younger ages and at higher rates than youth of other ethnicities (Majumdar, Chambers & Roberts, 2004). Researchers suggest that the incidence and prevalence of HIV/AIDS among Aboriginal Peoples also affects youth at higher rates (Majumdar, Chambers & Roberts, 2004; B.C. Aboriginal Task Force, 1999). Specifically, between 1979 and 2008, 19.3% of reported new AIDS cases among Aboriginal people were youth and young adults between the ages of 15 and 29, compared with 14.8% among non-Aboriginal people in the same age group. In 2003, a higher percentage of Aboriginal Peoples tested positive for HIV at a younger age when compared to non-Aboriginal persons. However, these statistics suggest that the Aboriginal population receiving an HIV/AIDS diagnosis is more likely to occur among the Aboriginal youth population between the ages of 15 to 29 (Public Health Agency of Canada, 2004; 2007; 2010). The Public Health Agency of Canada (2010) reported that

Aboriginal youth are acquiring HIV and AIDS at significantly higher rates than non-Aboriginal youth. Results indicate that the proportion of positive HIV test reports among Aboriginal youth display a generally increasing trend, from 28.8% of positive HIV test reports in 1998 to 40.9 % in 2008 (PHAC, 2010). More studies are required in order to fully understand the reasons why the Aboriginal youth population is included in more APHA diagnoses, as there has been very limited research in this area. One reason may be that there has been a significant increase in the Aboriginal youth populations in Canada since the latest census information (PHAC, 2010). Rowe & Ryan (1998) suggest that injection drug use appears to be an important factor for rising infection. The risk factors described above suggest that Aboriginal Peoples are disadvantaged in many ways and are over-represented in the incidence of HIV in Canada. Again, little research exists to understand this and to describe the experiences of Aboriginal Peoples who are affected and infected by HIV.

There are some limitations when interpreting the data reported by the PHAC, as there are two provinces in Canada that have not reported ethnicity since 2003, Ontario and Quebec. Both provinces have opted out of the national tracking system in hopes of improving on the validity of surveillance data. At this time, these two provinces are not included in the Canadian statistics on HIV/AIDs. Therefore, one must consider that at this time, the available data does indeed suggest that the Aboriginal youth populations are over represented in reported HIV and AIDs diagnoses. New cases that remain unknown would certainly increase the actual numbers, adding to the statistical facts that the Aboriginal youth populations who have HIV/AIDs are increasing.

Canada's Aboriginal population constitutes approximately 3% of the overall general population, with approximately 60% of that population being younger than 30 (CAAN, 2002). The average growth of the Aboriginal population is estimated more than double the rate of the rest of Canada and the Aboriginal youth populations is expected to increase 1.4% per year between 1996 and 2011 (Human Resources Development Canada, 1999). The spread of HIV among Aboriginal youth is a concern and has emerged as a dramatic increase in Aboriginal youth testing positive for HIV (Health Canada, 2000).

#### 2.7. Injection Drug Use and HIV/AIDS – Aboriginal communities.

Researchers have found that injection drug use (IDU) has been documented as being a strong risk factor for HIV infection within the Aboriginal population (Mehrabadi, Craib, Patterson, Adam, Moniruzzaman, Ward-Burkett, Schechter & Spittal, 2008; Craib, Spittal, Wood, Laliberte, Hogg, et al., 2003). The findings reported in these studies indicate that the incidence of HIV/AIDS infection among Aboriginal IDUs in Vancouver's downtown eastside is twice as high as the incidence among IDUs of other ethnicities. The numbers of Aboriginal people infected with the HIV is much higher than expected; the percentage of Aboriginal participants who were APHA accounted for twenty-five percent of the group, yet the Aboriginal population overall make up about 4% of the total population in B.C. (Mehrabdi et al. 2008).

#### 2.8. Mainstream Research and Aboriginal Peoples

Research about Aboriginal Peoples conducted through a European lens has contributed to the process of labelling and dehumanizing Indigenous peoples with many publications perpetuating this misinformation and stereotypes (Dunbar Jr., 2008). There is limited research conducted by Aboriginal Peoples that has allowed us to define

ourselves (Dunbar Jr., 2008; Absolon & Willett, 2005; Kovach, 2005; Battiste, 2000).

The process of gaining control of the research process is vitally important in the decolonization movement and in generating accurate knowledge for Indigenous peoples (Kovach, 2005). In fact, guidelines for conducting research with Aboriginal Peoples have been adopted by the Canadian Institutes of Health Research (CIHR) and other guidelines such as creating an ethical space when conducting research with Aboriginal Peoples are well used (CIHR, 2007; Ermine, 2007). Over time, despite lapses and misunderstandings, Aboriginal peoples have recognized the importance of appropriate and meaningful research within their communities. In addition, new methodologies have been adapted and developed, mostly by Aboriginal scholars, which are more congruent with Aboriginal epistemology. Currently, approaches to research reflect these changing methodologies which directly link to the Aboriginal peoples wanting to be involved in the research from the onset, implementation to the final results.

Participatory research (PR) is a methodology that encourages critical, collective participation by all members of the research process and has emerged as a popular methodology amongst Aboriginal researchers in Canada (Kovach, 2005; McIntyre, 2008). This method seeks to improve the quality of life of the people being studied by involving them in the research process and by utilizing their life experiences and knowledge in the search for relevant solutions to their problems (Park, Brydon-Miller, Hall and Jackson, 1993). Another example of appropriate methodology is the generation of knowledge and data collection through use of oral transmission. For generations, Indigenous oral knowledge was not considered a legitimate form of transmitting and understanding knowledge (Battiste, 2000). However, in recent decades, Indigenous

scholars have been empowered by a decision made by the Supreme Court of Canada in 1997 (*Delgamuukw v. the Queen*) which mandated that Indigenous oral traditions be respected and included in generation of knowledge (Battiste, 2000). This decision legitimized the historical and cultural tradition of oral stories that may more accurately represent Aboriginal Peoples and encourages empowering cultural aspects within the research realm, including, but not limited to, traditional knowledge conveyed orally. The inclusion of appropriate methodologies for Aboriginal communities in the context of research is directly related to how a project will succeed or not succeed. In regards to the use of PR with Aboriginal communities, much healing has begun to occur and the future of research should include Aboriginal peoples working alongside non-Aboriginal researchers, with the same goal of improving the quality of life.

## 2.9. Identity

Recently, there have been efforts to understand the psychological and psychosocial aspects of the impact of HIV/AIDS with Aboriginal communities. In my MA research, findings suggested that when a person walks on the journey of healing, that they experience emotions linked to changing their identity, as a person who is HIV positive (McKay-McNabb, 2005). In regards to this change in identity, individuals may come to terms with their diagnosis/illness; they may reach the point of acceptance, which then allows for them to include being HIV positive as a part of their individual identity.

The concept of identity is difficult to describe. Identity is defined as the condition of being oneself, the character as to who a person is (Collins, 2011). Historically, there have been numerous psychological theoretical concepts developed about identity. For this research, the theoretical foundation that was selected had numerous similarities to a

traditional concept of identity, as explained by an Anishanabe Elder, Betty McKenna (2009). The stages of development as described by Eric Erikson (1964) are related to stages of development as described by Elder McKenna. Erikson's theory of identity is related to the scheme of the life cycle, to ego development in the form of psychosocial phases that relate to general styles of relating, and to coping with the environment (Fadima & Frager, 2002). In the late 30's, no other psychologist had documented anything about development and identity with Indigenous populations. Erikson sought to learn about why native populations felt conflicted by the current general population value system. He described that the current traditional tribal values learned in early childhood were in contrast to those they were learning in the white middle class school systems (Fadima & Frager, 2002). Erikson took the time to visit a number of American Indian reservations and settlements to understand more about Native American's value systems, child development and personality styles within those populations. Experiencing firsthand the differences of worldviews and concepts, the Native communities provided him with new insights to a cross-cultural worldview, which ultimately resulted in evolving his theoretical foundation (Fadima & Frager, 2002). Erikson's theoretical focus on healthy personality development was strongly influenced by firsthand knowledge of other cultures and Native Americans certainly had an influence on his theories.

Erikson's eight stages of human development 'epigenetic' model was one of the first psychological theories to detail the human life cycle from infancy to adulthood and old age. He suggested that each element developed on top of the other parts (Erikson, 1964; Marcia, 1999). McKenna (2009) described a developmental system where there are seven stages of development through the "rapids of life", each stage has specific levels of

development required to move on to the next stage of development from the fetal stage to death. McKenna (2009) describes these stages through the traditional knowledge she carries as an Anishanabe. Both Erikson and McKenna share similar qualities with their stages of development being characterized by a specific developmental task, or crisis that must be resolved in order for the individual to proceed to the next stage.

The concept of identity that Erikson developed was built upon childhood identifications and the individual's own organization of childhood, which then developed into a pattern throughout their adolescence to old age. This identity, based on continuity with one's past, provides meaning for one's present and a direction for one's future (Erikson, 1964; Marcia, 1999). McKenna (2009) described the concept of developing identity through the traditional knowledge she holds as an elder. Identity is understood as being connected to one's life as one navigates through their stages of development. She describes how when children are encouraged to be in tune with their identities, they will develop and progress through the *rapids of life*. The concept of developing an identity is a collective community experience. However, if they do not progress, problem solve and grow, their identities remain stagnant and they do not mature through the stages. She indicated that some individuals in Aboriginal communities were affected in the progression, when they were taken from their homes and forced to attend residential schools (McKenna, 2009).

Chandler (1994) suggests that high levels of emotional distress and problems that Aboriginal Peoples face such as depression, anxiety, substance abuse, and suicide are closely related to problems of individual identity and self-esteem. These ongoing issues and stresses are related to the impact of colonization, bureaucratic surveillance and

technocratic control (Kirkmeyer et al, 2009). The process of identity occurs throughout human development, starting as an infant, through childhood, and adolescent and finally to adulthood. As individuals develop through stages throughout their lives, they ultimately develop a sense of identity.

According to psychological research, the development of a healthy psychological identity occurs as a process throughout the lifespan. Adolescence has been shown to be a critical period of identity development (Sigelman, 2007). The concept of identity refers to a firm and coherent definition of who you are, where you are going and how you fit into society (Lefton et al., 2008). The theory generated by Erik Erikson suggests that as individuals navigate through each stage of development, they attempt to negotiate a specific crisis and thereby move forward towards greater maturity (Lefton et al., 2008; Erikson, 1968; Marcia, 1999). Erikson's theory suggests that if an adolescent fails to successfully negotiate the crisis of identity vs. identity diffusion, they will fail to form a solid identity, which leaves the adolescent confused about adult roles and unable to cope with the demands of adulthood (Lefton et al., 2008; Erikson, 1968; Marcia, 1999). McKenna's rapids of life contrasts to Erikson's theory by McKenna's Indigenous way of understanding growth as being a collective and community experience to assist the growth, where Erikson's theory suggests it is more individualistic in regards to developing identity.

As thousands of Aboriginal youth were institutionalized within the walls of Indian residential schools, generations of youth were not successful in completing the cycles of identity as described by Erikson. Therefore, it is important for this thesis to address the paucity of psychological literature that describes the loss of identity that Aboriginal



communities face due to the historical and current traumas. The focus on HIV and AIDS will not take away from theory development in this area; in fact, results may reveal important aspects of identity formation as a result of residential school/historical trauma.

#### 2.10. Treatments of HIV/AIDS

Due to the discovery of powerful antiviral drugs over the past decade, the course of the disease has been transformed (Bayer & Oppenheimer, 2000). With compliance to treatment and medication, individuals living with HIV have the potential to live healthier, longer lives before developing symptoms of AIDS (Bayer & Oppenheimer, 2000). More importantly, death is not as prevalent for individuals living with HIV as it was in the first decades of the infection. Therefore with the advancement of treatment options for those diagnosed with HIV, there is hope and potential to be able to live a “closer to normal” life and reach an old age.

Some challenges remain in regards to treatment, such as when a person who is diagnosed with HIV, each province and territory has a different program for subsidizing drug costs for their residents, which results in some provinces and territories providing better drug plans/coverage and care than others (Canadian AIDS Treatment Information Exchange, 2009). The Federal Government in Canada has a legal relationship with Aboriginal peoples in regards to accessing treatment. Specifically, the Non-Insured Health Benefits Programs (NIHB) is a national health program administered specifically for eligible members of First Nations status individuals. This is a supplemental program that was designed to meet medical treatment for First Nations peoples. However, the plan covers only the lowest-cost drug alternative, known as the generic drug (CATIE, 2009). The various political levels of funding may present another barrier for treatments, as

some HIV and AIDS medications are not the same when supplied in the generic form, which may result in limitations in treatment. The process of deconstructing this medical coverage for treatment of HIV/AIDS clearly demonstrates how political the health care of Aboriginal peoples is, and other marginalized groups (poverty, immigrants, etc.) and results in a myriad of problems when treating HIV/AIDS in Canada.

#### 2.11. Denial of Treatment From Medical Professionals

Perhaps one of the most surprising facts, which likely had a devastating impact on those infected with HIV in the first decades of the disease, was the denial of care to some people who were HIV positive. Previous researchers suggest that Aboriginal people diagnosed with HIV and AIDS experience layers of stigma within their community, which has led to isolation, ineffective social support and treatment (CAAN, 2011; Bruyn, 1999). Many doctors in the early days of the epidemic, in the eighties believed that they did not have an ethical obligation to treat individuals infected with HIV. In a study of primary care practitioners, half reported that they would not care for patients with HIV infection (Bayer & Oppenheimer, 2000). Some of these challenges have ameliorated over time and stigmatization and discrimination are not as prominent as it was during the approximate onset of the illness in Canada in 1980. Unfortunately, in the Aboriginal population, the added stigma and discrimination reported by individuals who attempt to access care and treatment suggest that the HIV stigma combined with racial prejudice are increasing and are affecting those living with HIV and AIDS. These barriers contribute to difficulties APHAs encounter when attempting to access medical and support services both inside and outside of Aboriginal communities (CAAN, 2008). These health care challenges and limitations may result in those living with HIV and AIDS not accessing

the appropriate level of care; this barrier may impact their health along with their ability to live with the disease.

## 2.12. Psychology and Aboriginal Peoples

There is limited research conducted in the field of psychology about Aboriginal peoples. Of that research that has been conducted, the results suggest that Aboriginal people have much higher rates of mental health problems than non-Aboriginal people (Söchting et al., 2007). The higher rate of mental illness may be directly related to the effects of colonization, contact with European settlers, and the subsequent changes in the Aboriginal lifestyle (Söchting et al., 2007). Findings suggest that Aboriginal Peoples experience higher incidence of traumatic pasts (i.e. assault, sexual abuse) than the non-Aboriginal population (Barlow, 2002). The psychological effects resulting from Aboriginal Peoples being forced to attend the residential schools has just recently started to be investigated by psychiatrists who have proposed criteria for the upcoming Diagnostic and Statistical Manual for Psychological Disorders, Fifth edition (DSM-V). Brasfield (2001) suggests that the diagnostic term Residential School Syndrome be further investigated, as the features of this syndrome would be similar to the diagnosis of Posttraumatic Stress Disorder. Although this proposed diagnostic category is preliminary, it does acknowledge there were negative psychological effects resulting from attending residential schools and that children who attended these schools and their families suffered psychological effects from this forced policy with the effects that are continuing to affect Aboriginal peoples today.

Currently, there are discussions about whether there should be a diagnosis for the future revision of the DSM, which will be called “complex post-traumatic stress

disorder” (complex PTSD) or “disorder of extreme stress not otherwise specified” (DENOS). This diagnostic category may provide a framework when assessing Aboriginal Peoples with a traumatic past (Söchting et al., 2007). Although, there is much to be done before this new criteria for diagnosis may be included in the DSM, such as further investigation and research. One suggestion that would be beneficial is including Aboriginal peoples when deciding upon the criteria, as they should have a voice in this decision.

### 2.13. Intergenerational Trauma

The consequences of colonization have resulted in intergenerational effects of trauma, which may be linked to mental health challenges. The Diagnostic and Statistical Manual IV-TR (DSM-IV-TR) (APA, 2002) introduced post-traumatic stress disorder (PTSD) in the third edition. The mental health implication of stress and intergenerational trauma has recently emerged as a significant health crisis within Aboriginal communities. There are currently researchers trying to identify the impact of the intergenerational trauma that Aboriginal Peoples have experienced and how it is related to mental health (Söchting, et al., 2007). Researchers suggest there are layers of trauma within an Aboriginal person that underlie the mental health challenges they exhibit. The intergenerational trauma that many Aboriginal people endure may be passed down through generations and re-experienced unless they seek healing and support (Waldram, 2004).

### 2.14. Psychology, Mental Health, and Aboriginal Peoples

Gone (2010) describes how prior to contact, the existence of mental health was connected to the Indigenous experiences of spirituality, traditions, personhood, social

relations, wellness, and cultural identity. Once contact occurred, Native Americans experienced warfare, disease, relocation, containment, impoverishment or deliberate policies of cultural eradication (Gone, 2010). The results of contact in regards to mental health have emerged as a limitation or barrier for supports within contemporary Native American communities. Indigenous individuals have become suspicious of the ultimate relevance and utility of conventional psychological interventions proffered by European American mental health professional (Gone, 2010). The culture of European mental health became a taboo practice within Aboriginal communities.

That's kind of like taboo. You know, we don't do that. We never did do that. If you look at the big picture – you look at your past, your history, where you come from-and you look at your future where the Whiteman's leading you. I guess you could make a choice: Where do I want to end up? And I guess a lot of people want to end up looking good to the Whiteman. Then it'd be a good thing to do. Go (to the) white psychiatrists in the Indian Health Service and say 'Rid me of my history, my past and brainwash me forever so I can be like the Whiteman.(Travelling Thunder, cited in Gone & Alcántara, 2007).

In regards to mental health and Indigenous peoples, there is virtually no empirical literature that documents the processes and outcomes of psychological services delivered to Native clients and communities (Gone & Alcántara, 2007; Witko, 2006). Researchers interested in identifying effective mental health interventions reviewed the literature and found that only two controlled studies out of fifty-six included data pertaining to the treatment of Native Americans with mental health problems in the United States (Gone & Alcántara, 2007). The results of these studies suggested that treatment outcomes have not been empirically assessed or reported for American Indians and there is much to learn. In regards to the Aboriginal population in Canada, there also remains a gap in the research. This remains to be a challenge if and when Aboriginal peoples may decide to access western mental health supports. More importantly, when an individual first learns about

their HIV status, there is a myriad of emotions and feelings that one experiences. If western mental health supports continue to not be accessed by the Aboriginal population, their specific needs will remain unknown within the western supports. Some traditional supports may be utilized, yet there are limitations because many believe mental health practices are taboo within Aboriginal communities, as such how can Aboriginal community members access these supports when dealing with a life changing diagnosis.

Most cross-cultural research has been conducted in the United States with Black or Hispanic communities and HIV/AIDS; results suggest members of these cultures are over-represented in those diagnosed with HIV/AIDS (Boyd- Franklin, Alemán, Jean- Giles & Lewis, 1995). Although in the United States the population of Aboriginal people/Native Americans is lower than the Black or Hispanic communities, rates remain higher than in the Caucasian community (Myers, Bullock, Calzavara, Cockerill, Marshall & George-Mandoka, 1999). In Canada, the Aboriginal HIV and AIDS prevalence rates have been studied in limited sub-populations such as prison inmates, drug treatment programs, injection drug users, homosexually active men and people with haemophilia (Martin 1993; Rekart; 1993; Rohton 1993, as cited in Myers, Bullock, Calzavara, Cockerill, Marshall & George-Mandoka, 1999).

Cross-cultural health care and programming available to Aboriginal Peoples living with HIV is limited in Canada and is often located in large cities (i.e. Toronto or Vancouver). However, if these services could exist in more locations in Canada, researchers suggest that it would improve Aboriginal People's health (CAAN, 2002; CAAN, 2005; Ship and Norton, 2001).

In the U.S. Cervantes, Kappos, Dueñas, & Arellano (2003) developed a model for gender specific substance abuse programs. These researchers addressed the gap in culturally appropriate programs by evaluating a culturally focused substance abuse treatment and HIV and AIDs prevention program for Hispanic women in Los Angeles. The experiences of Hispanic Peoples in the United States may parallel our Aboriginal Peoples in Canada as both populations are likely to experience a range of risk factors, including cultural disenfranchisement, acculturation stress, and lack of health care and inadequate support systems (Cervantes et al. 2003). However, there are distinct differences in these populations since Hispanic Peoples have been identified by the U.S. government as being immigrants or refugees to the United States. Although there are disagreements about who were the first peoples due to the borders being contested between Californian and Mexico. In Canada, Aboriginal/Indigenous Peoples are “First Peoples” and were subjected to colonization. Results of the study conducted by Cervantes, et al. (2003) suggest that treatment programs that integrate sensitivity of needs and are culturally competent may be more effective in producing positive changes in drug use outcomes.

In Canada, Cain, Jackson, Prentice, Mill, Collins and Barlow (2011) findings suggest that front line service and support workers should be aware of the potentially important role that cultural traditions may play in assisting Aboriginal people to cope with mental health and the challenges of living with HIV. Additionally, the results suggest that if Aboriginal community members are encouraged to explore Aboriginal approaches to healing, it assisted them to reconnect with culture, traditions and ceremonies, which ultimately assisted them to cope with mental health issues and

developing their HIV identities. Cain and colleagues (2011) further suggest that blending western and traditional approaches with culturally appropriate and comprehensive support to Aboriginal people living with HIV and AIDS is most effective in development of coping mechanisms.

To demonstrate the cultural perspectives within the context of this study, I have utilized definitions developed from Burhansstippanov's work in health care and Native American studies. She identified that there is limited agreement amongst researchers about definitions in regards to cultural perspective and she identified definitions to assist in understanding cultural perspectives of Native Americans and health care professionals. Burhansstippanov's, (1999) definitions in regards to culture and Native Americans will be utilized in this study. She defines culturally competent as being culturally sensitive, relevant, and appropriate. Culturally relevant is defined as being specifically relevant to a definite culture, meaning concepts make sense to a target population, symbols and images draw attention of a target population. Culturally sensitive is defined as an intervention being respectful to specific cultures beliefs, practices and so on. She suggests that some interventions, such as PAP tests will never be culturally sensitive, but they can be made culturally sensitive, for example, when they are done modestly by a female practitioner. Culturally appropriate is defined as being respectful, relevant to a specific culture and literacy issues. For purposes of this research, I will use the term "culturally relevant" to describe HIV/AIDS interventions for Aboriginal individuals and families that make cultural sense.

#### 2.15. Worldview



Prior to contact with Europeans, Aboriginal Peoples had social, political, economic and cultural structures that originated from their specific worldviews, were based on oral storytelling, and provided healing (Miller, 1997; Poonwassie & Charter, 2005). Colonization resulted in the loss of social and kinship structures, which included gender, parenting and social role models. This loss resulted in devastating psychological affects for many Aboriginal Peoples (Poonwassie & Charter, 2005; Subia Bigfoot & Dunlap, 2006). As researchers write about traditional approaches to healing, it is important to keep in mind the fact that Aboriginal cultures are diverse and vary in cultural protocols. Psychological healing traditionally for Aboriginal communities often consists of storytelling, teaching and sharing circles, role modelling, and participation in ceremonies such as the sweat lodge and the vision quest. The old people, the elders or community members who had specific training for conducting these traditional healing methods conducted the traditional and cultural ceremonies. These methods of healing and helping occurred for multiple generations within Aboriginal Peoples' cultures and were consistent with their worldviews; these healing methods assisted in the ability for psychological healing and are considered to be culturally appropriate for Aboriginal Peoples today (Subia Bigfoot & Dunlap, 2006; Moodey, 2005).

Subia Bigfoot & Dunlap (2006) describe how the use of Indigenous oral tradition and teaching through storytelling is an effective way to provide psychological support. It is through the sharing of ideas, feeling, beliefs and expectations in the storytelling experience that elders, teachers, guides, and helpers provided help and healing for community members struggling with disease or distress. Researchers suggest that it is through this method of storytelling that clinicians who serve Aboriginal people can

encourage a therapeutic relationship by providing an opportunity to facilitate culturally safe mental health supports. For example, Sue & Sue (2008) suggest that programs and supports for mental health care with Native Americans are more effective when they engage the community and are oriented towards the entire community rather than individuals. When providing services within a small Aboriginal community, it would be important to ensure that elders and leaders in the community are consulted and engaged in the development of such services to ensure safe and adaptable supports and services may be provided.

#### 2.16. Research Question

This research study integrated cross-cultural mental health research in the field of psychology, life experiences and stories about HIV/AIDS within Aboriginal communities, and information of historical colonization of Aboriginal Peoples. This integration, combined with collection of qualitative data, has led to generation of a theory describing Aboriginal communities' experience of HIV and AIDS in Canada today. The Canadian Psychiatric Society (2003) reported that due to the effective treatment of HIV, those living with HIV live longer and face more mental health problems. Therefore, it is imperative that Aboriginal Peoples living with HIV and AIDS or being affected by the virus have an opportunity to voice their experiences and inform others about the challenges they face. In an effort to honour the historical consciousness and traditional epistemology of Aboriginal Peoples, I have attempted to be inclusive of "communities" and have asked individual participants to discuss the challenges they experience, but also the experience of their community (i.e., Nation, geographical community, family, etc.).

The purpose of this research study was to provide an opportunity for Aboriginal community members in Canada to describe their experience of living with or being affected by HIV/AIDS. The specific research questions were: (1) what are the experiences of Aboriginal individuals who have been diagnosed with HIV/AIDS? (2) What are the experiences of Aboriginal community members whose relatives have been diagnosed with HIV/AIDS (those affected by HIV/AIDS); and (3) what recommendations/guidance can these Aboriginal Peoples give to this researcher who is developing a culturally-relevant psychological theory that will assist with healing.

Interview data were integrated with literature to to develop a theory describing the effects of HIV/AIDS on Aboriginal communities in Canada; this theory includes suggestions for effective psychological intervention from a cross-cultural perspective. Review of the current literature reveals there is limited existing research specifically on the experiences of Aboriginal Peoples in Canada who are affected by HIV/AIDS. This study provides us with a better understanding of what it is like for Aboriginal Peoples who live with the diagnosis of HIV/AIDS or the issues Aboriginal family members experience that are affected by a diagnosis of HIV and AIDS. It also helps to gain a better understanding of the impact that disclosure of the illness of HIV/AIDS has upon these individuals, their family members and their rural on-reserve , rural-off reserve and urban Aboriginal communities.

### 3. METHODOLOGY

*Probably most researchers who use our methodology (and certainly those who use only its procedures) have not reflected upon the assumptions that underlie the method presented in this book. Perhaps they assume that methodology evolves strictly from practice. Though it does to some degree, it is also considerably influenced by worldview, or the beliefs and attitudes about the world we live in (Corbin & Strauss, 2008, p. 5).*

Qualitative methods were chosen as the most appropriate method for answering the research questions (Corbin & Strauss, 2008; Charmaz, 2006; Glaser & Straus, 1967; Strauss & Corbin, 1998). It was the most appropriate method for my study because this method allows for the voices of the Aboriginal participants to emerge and provides space for Aboriginal individuals to share their stories. Specifically, grounded theory was employed to gain a better understanding of Aboriginal People's experiences living with or being affected by HIV/AIDS, investigated qualitatively by a First Nations researcher (McKay-McNabb, 2005). Qualitative interviews that encourage an exploration of personal experience will explore the reality of Aboriginal individuals living with HIV/AIDS and their family members. I also asked participants to reflect on the effects of HIV/AIDS within their rural on-reserve, rural off-reserve and urban Aboriginal communities.

The use of qualitative methods is also appropriate for conducting culturally relevant research. Similar research about HIV/AIDS has been conducted with the African American population in United States; the research findings and methods were found to be culturally relevant to the African American population (Tillman, 2002). Findings

generated by Tillman (2002) suggest that employing a culturally safe approach through use of qualitative methods assisted the research team to gain a better understanding of how various communities understand and experience the world. These researchers suggest that qualitative interpretive paradigms have been found to offer greater possibilities for co-construction of multiple realities and experience, which may ultimately lead to improvement of services for African American communities (Tillman, 2002). It is with this in mind that my research project may lead to further investigations and lead to improvements in the health of Aboriginal communities in Canada.

Qualitative research is a method of inquiry that extends beyond disciplines, fields and subject matter. Denzin and Lincoln (2005) describe qualitative methods as being a multidimensional approach to the interpretive understanding of the human experience. This method encourages researchers to analyze data from both critical and humanistic perspectives (Denzin & Lincoln, 2005). There are a variety of interconnected, complex concepts and assumptions that are used to define qualitative research (Denzin & Lincoln, 2000). This paradigm permits researchers to access and understand the inner experience of participants and to determine how meanings are formed in and through culture (Corbin & Strauss, 2008). Qualitative interviewing is utilized to help the researcher understand how individuals understand and experience the social world (Rubin & Rubin, 1995).

### 3.1. Overview of Grounded Theory

Qualitative methodology, specifically grounded theory, was used to create the opportunity for Aboriginal community members in Canada to share their experience with HIV/AIDS; previous research suggests that this is an area of their lives that remains largely a secret due to the stigma and discrimination attached to this disease (Jackson et

al., 2006). The qualitative interviews for this study were conducted using a humanistic, interpretative, indigenous approach focused on gaining knowledge through the understanding of how people experience the world and create meaning in their lives (Rubin & Rubin, 1995). The results from the interview will contribute to a theory describing how HIV/AIDS affects Aboriginal Peoples in Canada.

### 3.1.1. Development and History of Grounded Theory

Glaser and Strauss (1967) introduced grounded theory methodology in 1967 and they described strategies for qualitative data collection and analysis. Grounded theory emerged from the Chicago School of Sociology between 1920 and 1950 and is rooted in the symbolic interactionist tradition (Robrecht, 1995). This approach is based on the understanding that individuals are self-aware, able to see themselves from the perspective of others and able to adapt their behavior within a given situation. Human beings interpret and define the actions of others and knowledge is created through action and interaction (Corbin & Strauss, 2008). The collaboration between Barney Glaser and Anselm Strauss resulted in the development of grounded theory as a paradigm, method, and style of research (Boychuk Duhscher & Morgan, 2004).

From an historical perspective, theorists in the late 1930's generally utilized qualitative methods to generate data derived from research conducted in ways that were not systematic or rigorous, but were rooted in common sense and personal logic (Glaser & Strauss, 1967). This qualitative research methodology was criticized as being impressionistic and non-theoretical, even though the goal was to develop and construct theory. At this time, quantitative researchers were making great strides in producing accurate evidence and in translating theoretical concepts into research projects. The term

“empirical” research became popular and was related only to quantitative studies that used randomized sampling procedures. Empirical research, at the time, included systematic inquiry, rules of evidence and a focus on issues such as sampling, reliability, validity, and hypothesis construction (Denzin & Lincoln, 2008). However, at this same time, qualitative researchers had not yet developed a methodology to the point that they could offer assurance that they were collecting accurate evidence to generate theory (Glaser & Strauss, 1967). Qualitative approaches to research were relegated to the role of preliminary or exploratory work leading to hypothesis testing and were not considered empirical at this time (Glaser & Strauss, 1967).

Over time, differing opinions emerged between Glaser and Strauss about how to conduct grounded theory, which ultimately resulted in each researcher progressing in the development of their own methodological concepts: Glaserian and Strausian (Kelle, 2005). This ultimately resulted in a split between the two, which occurred soon after a publication by Strauss in 1987 about qualitative analysis. Following this publication, Strauss collaborated with Juliet Corbin on another publication about qualitative analysis and grounded theory. In 1992, Glaser published a book that criticized Strauss and Corbin’s previous publication and highlighted the differences in opinion from his point of view. Ultimately, Glaser suggested that Strauss had deviated from the intended form of grounded theory (Kelle, 2005). From this point, each methodology took on distinct theoretical concepts. Thus, Glaser and Straus ultimately both became leaders in qualitative methodology.

As qualitative methodology became more sophisticated, grounded theory researchers combined the depth and richness of qualitative and interpretive inquiry with

the logic and systematic rigor of analysis. Through the amalgamation of the finest of both processes, grounded theory, as we practice the method today, emerged (Walker & Myrick, 2006). Glaser and Strauss redirected the focus of qualitative inquiry from methods of data collection to strategies for data analysis that challenged views about theory construction (Charmaz, 2008). The traditional version of grounded theory developed by Glaser and Strauss was an inductive and analytic process made up of coding, constant comparison, and theoretical sampling.

Essentially, these two methodologists suggested that systematic qualitative analysis (i.e., use of the constant comparative method in analysis) had its own logic and would encourage the generation of theory. Strauss and Corbin (1998) expanded on the methodology proposed by Glaser and Strauss and defined steps in data analysis to include the following: (1) simultaneous data collection and analysis; (2) constructing analytic codes and categories from data; (3) using the constant comparative method; (4) advancing the theory development during each step of data collection and analysis; (5) writing memos which assist the researcher to define relationships between categories to identify gaps; (6) sampling geared towards theory construction; and (7) conducting the literature review after developing an independent analysis (Charmaz, 2006).

However, not all methodologists agreed that Glaser and Strauss' (1967) methodology was the appropriate use of grounded theory. Specifically, Glaser (1992) suggests that their theory and procedure 'force' data and analysis into preconceived categories, which contradicts the fundamental tenets of grounded theory.

### 3.1.2. Differing Opinions



There has been continued agreement on the purpose of grounded theory, specifically the discovery of a theory that is true to the participants' experiences, one that makes sense to the individuals being studied, and fits within the context and social situation of the studied phenomenon (Boychuk Duchscher & Morgan, 2004). Although, since the inception of the analytic process of grounded theory in the 1960's different versions have been developed and used by various researchers (Charmaz, 2000; Robrecht, 1995; Seale, 1999). The most notable modification was changes to the analytic process of grounded theory developed by Strauss, which resulted in Glaser and Strauss developing theory and practice in different directions. The original joint endeavor split into the Straussian and the Glaserian models of grounded theory (Boychuk Duchscher & Morgan, 2004; Walker & Myrick, 2006)

Glaser continued to focus on an emergence model of theory generation in which theory rises directly out of the data through rigorous processes of verification. He advocates for combating impressionistic influences by continually refocusing and connecting emerging theory to data (Boychuk Duchscher & Morgan, 2004). His unrelenting emphasis on theory emerging from the data is the primary feature that distinguishes Glaser's approach to grounded theory from approaches advocated for by other grounded theory researchers (Boychuk Duchscher & Morgan, 2004).

Strauss moved toward conceptualizing theory development as the interplay between the researcher and the data, a shift, which Glaser criticized. His critique suggests that Strauss's approach involves a prolonged fracturing of data through directive questioning that forces preconceived conceptual descriptions rather than allowing theory to emerge (Boychuk Duchscher & Morgan, 2004; Walker & Myrick, 2006). However, it

has been suggested that the approach advocated by Strauss and Corbin might simply be articulating the natural cognitive processes that are used when things are compared (Walker & Myrick, 2006).

Differences between the Glaserian and Straussian models of grounded theory have been the focus of extensive discussion (e.g. Boychuk Duchscher & Morgan, 2004; Walker & Myrick, 2006). Of relevance to this study are the concerns related to the data analysis process. These issues include differences in coding procedures and the role of deduction in grounded theory. Coding is the fundamental analytic process used by researchers to move data from transcript to theory (Walker & Myrick, 2006). The coding process in the original version of grounded theory is comprised of two procedures: substantive and theoretical coding (Glaser & Strauss, 1967). Substantive coding has two sub phases, open and selective coding, which focus on the development of categories and their properties. Theoretical coding takes place at the conceptual level through the integration of categories developed during substantive coding into a hypothesis or theory (Glaser & Strauss, 1967; Walker & Myrick, 2006). Glaser is generally considered to have remained true to classic grounded theory while elaborating in more detail concepts such as theoretical sampling, theoretical coding and the use of theoretical memos (Heath & Cowley, 2003). Glaser's method fractures and selects in substantive coding, then uses theoretical coding to relate and integrate (Walker & Myrick, 2006). The use of constant comparison and circular analysis of the relationship between codes leads to advanced coding and higher levels of theoretical conceptualization (Boychuk Duchscher & Morgan, 2004). Glaser advocates for coding methods in keeping with the original

version of grounded theory in which codes represent the essential relationship between data and theory (Glaser, 1992; Walker & Myrick, 2006).

Strauss and Corbin focused on developing analytic techniques to provide guidance to novice researchers, an approach that has been criticized for creating a rigidity and focus on emergence that some see as problematic (Heath & Cowley, 2003). Strauss and Corbin's coding process (1990, 1998) involves three phases: open, axial, and selective coding. Open coding is an interpretive process in which the data is broken down analytically to provide insights into the phenomena reflected in the data through the use of constant comparison (Corbin & Strauss, 1990). Events, actions, and interactions are compared for similarities and differences and are then given conceptual labels. The category is further broken down into specific properties (characteristics or components) and their dimensions (variations of a property) (Corbin & Strauss, 2008; Corbin & Strauss, 1990). Open coding stimulates generative and comparative questions that serve to guide researchers in future work in the field (Corbin & Strauss, 1990).

### 3.1.3. The Role of Reasoning

Total adherence to the inductive nature of the analytic process was fundamental to Glaser and Strauss's original conceptualization of grounded theory (Boychuk Duchscher & Morgan, 2004). Glaser argued that induction was the primary process involved in grounded theory with the researcher moving from the coded data to conceptual generalizations to theory through the process of constant comparison of new and old data (Glaser, 1992). For Glaser, constant comparison was the only way to verify the accuracy of the emerging theory.

According to Strauss and Corbin, the coding process involves a constant interplay between inductive and deductive thinking by continually verifying the interpretation of data (Strauss & Corbin, 1990). Deduction is seen as part of the interpretive process, which is used to adjust for potential human error in the process of data analysis (Walker & Myrick, 2006). Although theory emergence holds a place in Straussian grounded theory, deduction and verification dominate analysis (Heath & Cowley, 2003; Strauss & Corbin, 1990).

Glaser's fundamental criticism of Strauss and Corbin's application of grounded theory methodology is what he described as the interruption of true emergence that occurs from asking too many preconceived and substantive questions that distract the researcher from what is happening in the data (Boychuk Duchscher & Morgan, 2004; Glaser, 1992). Glaser contends that the questions used by Strauss and Corbin force a conceptual description of data rather than allowing the articulation of emerging theory. He argues that this approach is not just a different version of grounded theory but rather a completely different research method (Boychuk Duchscher & Morgan, 2004; Walker & Myrick, 2006). In his later works, Glaser expands his view of theory emergence to suggest that emergent categories are objective, general, abstract, and devoid of interpretation (Charmaz, 2008).

Charmaz (2008) suggests that there are four fundamental tenets that define the grounded theory approach: a minimization of preconceived ideas about the research question and the data; the use of simultaneous data collection and analysis to inform each other; openness to varied understandings and explanations of the data and a focus on data analysis to construct theory. Charmaz (2006) described grounded theory method as a set

of principles and practices. In contrast to being prescriptive, which previous grounded theorists have suggested, she indicated that grounded theory methods are ‘flexible guidelines’. She further suggests that the traditional grounded theorists, such as Glaser, Strauss and Corbin have provided researchers, academics and students with explicit methods for analyzing processes (Charmaz, 2006).

Heath and Cowley (2003) suggest that rather than debating the relative merits of the two approaches, researchers should select the method that best suits their cognitive style. The idea that the Straussian method brings to light the natural cognitive processes involved in making comparisons resonates with me and for that reason I have chosen to utilize the approaches to analysis advocated by Strauss and Corbin (1998) and Corbin and Strauss (2008).

The grounded theory approach encourages researchers to remain close to their studied worlds, facilitating the researcher’s ability to develop an integrated set of theoretical concepts from their empirical materials (Charmaz, 2005). This method encourages synthesis when interpreting the data and also to shows how conceptual relationships emerge from the data. Charmaz (2005) describes grounded theory as being a research method that enables the researcher to focus on their data collection and to build inductive, middle range theories through successive levels of data analysis and conceptual development. A grounded theory research method encourages the development of a template for doing qualitative research that is linked with a positivist, western approach (Glaser, 1992). The theoretical framework provides the original foundation focused on logic, analytic procedures, comparative methods and conceptual developments. These are assumptions of the external world along with the assumption of

an unbiased observer who discovers theory (Glaser, 1992; Charmaz, 2006). By asking questions and making comparisons of the data, Strauss and Corbin (1998) encourage developing an analytic platform for the data to emerge as a theory. More recently, Strauss and Corbin (2008) procedures encourage the researcher to have more direction in the research process, which includes expanding on the analytical tools.

Grounded theory research conducted in the area of HIV/AIDS with Aboriginal communities in Canada has been limited. Yet qualitative methods have been described as helpful for understanding the *meaning or nature* of experiences of conflicted or misunderstood groups (Strauss & Corbin, 1998). As previously mentioned, HIV/AIDS is becoming a part of Aboriginal communities in Canada and some have reported that this population is being affected at higher proportions than other cultures in the Canadian population (CAAN, 2007; Prentice, Mill, Archibald, Sommerfeldt, Worthington, Jackson, & Wong, 2011). Therefore, it is important to make an effort to try and understand just what this increase in HIV/AIDS means for the future of Aboriginal communities in Canada.

Specifically, Strauss & Corbin's (1998) methods of qualitative inquiry have been utilized in this study to provide a better understanding about the life experiences of Aboriginal communities in Canada living with and affected by HIV/AIDS. This method of inquiry will consist of directly asking individuals in this group about their life experiences. Strauss and Corbin (1998) suggest qualitative methods are useful when exploring areas about which little is known.

## 4. DATA COLLECTION

### 4.1. Ethics

Ethics approval for this study was obtained from the University of Regina Research Ethics Board (Appendix A). In addition, ethical guidelines presented by the Canadian Institutes of Health Research for Conducting Research with Aboriginal Peoples (2007) were followed. The two elders who assisted with giving me information about many of the traditional and cultural aspects of the study also guided the research in this project. As well this study relied heavily on the academic Aboriginal Ethical research protocols that have been introduced over the past five years, which continue to evolve ethical and respectful research methods for our Aboriginal peoples, such as Ermine's Ethical Space. Recently, the Canadian Institutes of Health Research (CIHR) have worked closely with Aboriginal and Non- Aboriginal researchers, academics and community members to build partnerships and generate culturally appropriate ethical guideline. Since the onset of my research the TCPS2 has been developed and includes many ethical protocols.

Some of our Aboriginal communities in Canada have developed specific ethical guidelines for researchers to follow when entering into partnerships with Aboriginal communities. For example, Marlene Brant Castellano (2004) describes Aboriginal Research Ethics; I utilized these guidelines throughout my research. The Brant Castellano (2004) guidelines were developed through consultations that occurred in the 1990s with Aboriginal communities and Aboriginal researchers. An Elder who attended the consultations shared his wisdom and knowledge; this wisdom and knowledge has been described as being responsible for a positive shift, moving the discussion away from a

negative focus (Brant Castellano, 2004). His words were in response to numerous participants' criticism and skepticism with previous Aboriginal research. The consensus of these community groups appeared to be: "We have been researched to death." The elder spoke with wisdom and respect and said, "If we have been researched to death," he said, "Maybe it's time we started researching ourselves back to life" (Brant Castellano, 2004). These significant and empowering words of one of our elders have guided me throughout my research process. I believe the research that has occurred for this study has been to assist Aboriginal community members who are APHA or have a family member living with HIV/AIDS to have a voice and create a platform for them to be heard.

#### 4.2. Theoretical Sampling.

The main point of theoretical sampling is to explicate and verify the categories and the relationship between categories that emerge during the coding process (Fassinger, 2005). I used theoretical sampling as my recruitment method: I recruited participants who represent the groups affected by HIV and AIDS in the Aboriginal population in Canada (i.e., two-spirited, men, women, youth, injection drug users). The main point of theoretical sampling is to explicate and verify the categories and the relationship between categories that emerge during the coding process (Fassinger, 2005). These target groups were identified from review of the literature. I was guided in the recruitment by the method of theoretical sampling, so was open to recruiting additional participants throughout the study. Sampling ceased when saturation was reached (i.e., no new codes emerge when coding the transcripts), which avoids an unnecessary redundancy in the findings (Fassinger, 2005). Theoretical saturation occurs when gathering more data sheds no further light on the properties of theoretical categories (Charmaz, 2008; Corbin &



Strauss, 2008). Theoretical sampling can take the form of interviewing additional participants but also involves returning to existing data to look at incidents, scenarios, or events which support or challenge the emerging theory (Corbin & Strauss, 2008; Fassinger, 2005).

For this study, I utilized theoretical sampling, a method of grounded theory in which sampling continues concurrently with data analysis and is guided by the theory development (Corbin & Strauss, 2008; Boychuk Duchscher & Morgan, 2004).

Theoretical sampling has an indeterminate time frame in that the researcher cannot know in advance the nature or best source of the sample sought as it relates to emerging codes (Boychuk Duchscher & Morgan, 2004). The collection of new data and selection of additional participants is directed by gaps, unanswered questions, and underdeveloped ideas as they emerge in data analysis (Corbin & Strauss, 2008; Fassinger, 2005).

Returning to the field to collect further data continues until codes are fully saturated, elaborated upon and integrated into the emerging theory (Corbin & Strauss, 2008; Boychuk Duchscher & Morgan, 2004). This process is called “theoretical sampling”.

At the onset of data collection, I initially intended to conduct preliminary analysis of the interviews as they occurred. In the first two interviews, I did conduct the initial coding and preliminary analysis. At this point, interviews began to come in at a fast rate, which required my full attention. In order to conduct the interviews with the interested potential participants, often, I had to conduct the interview the day that they expressed their interest. At times this was possible, and others it was not. I continued to proceed and book interviews at appropriate times selected by the potential participants. The interview bookings proved to be a tremendous challenge, as at the time of our first contact and

discussion about the interview time and place, participants often indicated that the time and place that they agreed upon would work for the interview. However, when it came to them attending the booked appointments times, they often missed. This occurred with nine potential participants, who missed multiple appointment times and ultimately did not participate in the study. The reasons for this varied: for everyday life stressors (i.e. transportation, childcare, life events); challenges in their ability to communicate through emails or telephones; or addictions issues. In an effort to tackle the missed appointments, I set out to complete the interviews as quickly as possible to ensure I would reach a population that has challenges in their everyday lives, to ensure their voices were heard. The majority of the interviews took place within 24 hours of expressing interest in the study. Therefore the transcribing and preliminary analysis occurred following the final ten interviews.

Out of the first ten interviews, only two participants had been affected by HIV/AIDS. At this point in the interview process, I decided to directly focus on recruiting affected individuals. An extension from the University of Regina Research Ethics Board was sought and received in spring of 2010 in order to continue to gather interviews until theoretical saturation occurred. Similar challenges arose with the following ten interviews in regards to interviewing times. However, as I gathered these interviews, great efforts were made to transcribe as soon as possible, and conduct preliminary analyses. Although, further time constraints and challenges arose which did not allow for immediate transcription to occur, efforts were focused on listening to the interviews and making notes prior to the next interview. The following ten interviews occurred at two national Aboriginal HIV/AIDS workshops/conferences that I attended. At the twentieth interview,

I felt that at this point, I had reached saturation with the data collection. I also realized that there were numerous differences that had emerged across the interviews and was beginning to see two distinct theories emerge from the data, one for APHAs and one for those affected by HIV/AIDS. Originally, I had not expected such significant differences to emerge and spent a lot of time reviewing these differences in order to fully understand the differences.

Another challenge in the recruitment process was the ability to remain in contact with potential participants. As previously mentioned, the population that I recruited participants from faced daily challenges in their lives. Specifically, often times I had an Aboriginal AIDS Service Organization (AASO) HIV/AIDS support worker indicate via email or voicemail that they had someone who was willing to participate in my study. However, I was often required to interview them immediately. This took a lot of effort and the ability to be spontaneous with my schedule, which increased my level of stress in regards to keeping communication open with potential participants. I decided to conduct the interviews in a short amount of time to ensure that I would not lose their participation in the study. As a result, I began to book appointments with very little preparation time between interviews, which also prevented me from transcribing and conducting preliminary analysis, as the methodology suggests. The theoretical approach was adapted to ensure that I was able to gather life experiences of those who expressed interest.

#### 4.3. Criteria for Participation – Theoretical sampling.

I interviewed fourteen Aboriginal community members who have been diagnosed with HIV and AIDS (“affected” by HIV/AIDS) and six Aboriginal community members whose family members have been diagnosed with HIV/AIDS (i.e., “affected by”). In

total, 20 Aboriginal individuals living in Canada who have been affected by HIV and AIDS participated in the qualitative interview. Criteria for participation in this study were being: (1) HIV positive diagnosis/AIDs status; (2) a family member having been diagnosed with HIV/AIDS; (3) over the age of 18; (4) of self-identified Aboriginal identity. The term *affected* was defined for this study as any Aboriginal person who has an Aboriginal family member or friend living with HIV and AIDS. CAAN (2008) defines the term *Aboriginal Peoples Having HIV and AIDS* (APHAs) as those who have self-identified as being diagnosed with HIV and AIDS. This term will be utilized to describe the individuals in this study who self-identified as being Aboriginal and living with HIV and AIDS. It is also important to understand that Aboriginal Peoples include adopted and extended family members as part of their immediate family (Episkenew, 2009). The extended family units are the foundation of Aboriginal communities and include aunts, uncles, friends, cousins, etc. (Episkenew, 2009).

#### 4.4. Recruitment Sites

Participants were recruited from Aboriginal Service Organizations (ASOs) and agencies across Canada that provide support services for those HIV positive or affected by HIV/AIDS. These organizations were identified and an e-mail letter was sent to Executive Directors of these agencies asking them to assist with recruitment by putting up recruitment posters and forwarding my email through their email databases (see Appendix B for letter of request). These agencies include the following organizations: Healing Our Nations (New Brunswick), Canadian AIDS Treatment Information Exchange, Canadian Aboriginal AIDS Network (Ottawa, Ontario), Ontario Health Network, Nine Circles in Manitoba, All Nations Hope AIDS Network (Regina,

Saskatchewan), Saskatchewan, AIDS Program South Saskatchewan (Regina, Saskatchewan), Healing Our Spirit (British Columbia). These ASO sites were willing to provide aftercare and support to those individuals that participated in my study, if they required support after the interview. When my study received approval from the University of Regina Research Ethics Board (Appendix A) recruitment began. A description of the research study was posted (Appendix E) at these agencies (Appendix C) asking for volunteers for this study. HIV and AIDS are a very unique illnesses and confidentiality is of utmost importance. Participants were informed that only the researcher and the researcher's supervisor would know their identities. Their identities would be protected and they would be referred to in the research findings by a pseudonym.

The recruitment sites may have resulted in a limited sample of the population, as many individuals who did participate in the study were recruited by Aboriginal ASO support agencies. More importantly, the majority of the participants in this study were utilizing services and this was how they learned about the research. Unfortunately, other members of the community within the Aboriginal population who were not seeking supports or services from an ASO would likely not have had a chance to participate in the study. As well, with HIV/AIDs, numerous individuals have this illness and do not know they are infected. Therefore, this would also reduce the likelihood of their participation in this study.

#### 4.5. Qualitative Interview

Open-ended qualitative interviews were conducted with Aboriginal community members aimed at exploring their life experiences of being HIV positive or being

affected by HIV/AIDS. The open-ended interview questions encouraged an exploration of their day-to-day reality and challenges (Rubin & Rubin, 1995). This qualitative method of sharing life experience fits with the tradition, epistemology, and processes of Aboriginal communities who historically utilize oral methods of storytelling to transfer information (Jackson, Cain, Collins, Mill, Barlow & Prentice, 2000; Mill, 1997). Often, when the interview began, participants suggested that they preferred to start their story at the onset of their journey with the illness, as it assisted them to remain focused and share their experiences in a way that fit for them.

A face-to-face or phone qualitative interview was scheduled at a location and time that was convenient for the participant. Preferably, the interview was to take place at the agency where the participant found the recruitment poster. They were provided with the consent form upon arriving at the scheduled meeting via fax or email; they were asked to read and review and were asked to sign the consent form (Appendix B). Each participant received a copy of the consent form to keep. In the case of a telephone interview, I emailed, faxed or sent through the mail two consent forms, with an addressed stamped return envelope for participants to send the original signed consent form back to me. One of the challenges with the interview process was when the participant did not have a phone or did not have a place to access email/internet. This was a problem for nine of the potential participants, who ultimately did not participate in the study and a problem for three of those who did participate. When this occurred, I did make every effort to conduct interviews as soon as possible to ensure that those who were willing to share their experiences were supported to do so to the best of my abilities. The ASOs often advocated for potential participants to volunteer for this study and also passed along the

information (posters, emails, etc.) and I did reach saturation with this study. In future studies, childcare and transportation should be provided and would be very helpful to those who express interest to participate.

Rubin and Rubin (1995) describe the importance of establishing trust prior to delving into participants' private worlds. The qualitative interview method described by Rubin and Rubin (1995) was used to guide the interviewing procedures. I introduced the basic research questions and shared some of my experiences in order to create a collaborative relationship (see Appendix G for interview questions). Kovach (2009) described the inclusion of story narrative by both researcher and research participant as methodologically congruent with indigenous tribal knowledges. This rapport building throughout the interviews often assisted in setting the tone of the interview. As well, a traditional smudge of sweet grass, cedar or sage was offered at the onset of the interview if participants were agreeable. Often, the participants also smudged with their cultural smudge specific to their culture. Additionally, some participants chose to light a candle to honour their loved one who had left to the spirit world. Participants listened to my personal experiences of being affected by HIV and often their stories connected to my experience. I often spent time conversing with participants prior to the recording of the interview to establish a sense of respect, in person when there were in person interviews, through phone conversations prior to the interview, through email correspondence, as well as through social networking sites (such as Facebook and HI5). I described my life experience as an Aboriginal woman who was affected by HIV and AIDS. My previous research experience with Aboriginal Elders, youth and women abused by intimate partners suggests that Aboriginal participants who are interviewed by an Aboriginal

researcher start with a sense of shared worldview. In order to ensure that I understand the diversity of life experience and not overly assume a shared experience, I adopted a listening attitude that reflected my stance as a researcher. That is, I asked participants to expand on their experience, even if they had suggested that I understand their life experience. Specifically, my stance as an Aboriginal person, with life experiences of living in both urban and reserve settings, and my experiences participating in powwows and traditional gatherings, assisted me in my ability to listen to the life experience of the Aboriginal community members who participated in my study my study.

The specific interview questions that were explored are listed in Appendix G. The open-ended interview guided data collection; however, as recommended by Rubin and Rubin (1995) the interview questions were adapted as the process of joint data collection and analysis unfolded. It was anticipated that 25 interviews were to be conducted; sampling continued until theoretical saturation was achieved at 20 interviews (Strauss & Corbin, 1998).

#### 4.6. Interview Process

The qualitative interview created an opportunity to give voice to groups who have been silenced or marginalized while allowing for the importance of context and individual experience (Rubin & Rubin, 1995). Qualitative methods are most appropriate when the aim is to gain a better understanding of a process because the results of qualitative research allow an understanding of nuances and details of complex social phenomena (Ellsberg & Heise, 2005; Charmaz, 2008). Experiences relating to living with or being affected by HIV/AIDS often remain unspoken as personal life experiences are often stigmatized or discriminated against. This makes it difficult to understand the



subtleties and meanings that underlie these experiences which highlights the importance of providing the opportunity for Aboriginal community members to express their life experiences. This level of understanding is particularly important for research investigating the interaction between beliefs, attitudes, perceptions, and human behavior (Ellsberg & Heise, 2005).

The nature of this inquiry and questioning is sensitive and had the potential to be intrusive; participants were informed that they may answer all questions to the degree to which they are comfortable. Participants received and were asked to review and sign a consent form that outlined the research protocol, specifying that they are free to withdraw at any time, including withdrawal of the interview data following completion of the interview. Participants were informed that all information shared would be treated as confidential and that their names and identifying information would not be associated with the data. The interviews were approximately 1½ hours to 2 ½ hours in length and were digitally recorded for transcription and analysis. In the event that the participant should experience any discomfort as a result of the interview, an appropriate referral for support was offered through the ASO that they were connected to (see Appendix H for referral sources). However, no participant asked for additional referrals. Since they were recruited from agencies where they were already receiving services, the ethical responsibility to ensure that each participant received assistance was assured.

#### 4.7. Coding

Corbin and Strauss (1998) describe coding as the researcher interacting with the data using techniques such as: 1) asking questions about the data; 2) making comparisons between data; and 3) deriving concepts to stand for those comparisons while developing

those concepts in terms of their properties and dimensions. In this edition, the concepts of open and axial coding were described as a separate process while conducting data analysis (Strauss & Corbin, 1998). Strauss and Corbin (1998) originally developed these analytic techniques to provide guidance to novice researchers, and has been criticized for creating a rigidity and focus on emergence that some see as problematic (Heath & Cowley, 2003). However, I find this technique helpful and useful for answering my research questions and used the 1998 version to guide my data analysis, in the development of my theory.

Strauss and Corbin (1998) describe coding as the analytic process of mining the data, where one should dig beneath the surface of the data to discover the hidden treasures within. In the recent edition, the concepts of axial and open coding emerge as a process of breaking apart the data to identify concepts that stand for the data (Corbin & Strauss, 2008). This process requires that the researcher remain intuitive when analyzing the data and trust in one's self to make decisions while collecting the data. Another level of analysis included asking different questions in the following interview to dig deeper in order to gain a better understanding of the individual's life experience (Strauss and Corbin, 1998). In the recent edition, there was an adaptation from the original version of memo writing, where memos were a less structured process to assist in further development of the theory (Corbin & Strauss, 2008).

Coding is the fundamental analytic process used by researchers to move data from transcript to theory (Walker & Myrick, 2006). The coding process in the 1998 version described grounded theory as comprising two procedures: substantive and theoretical coding (Glaser & Strauss, 1998). Substantive coding has three sub phases: open, axial,

and selective coding, which focus on the development of categories and their properties. Theoretical coding takes place at the conceptual level through the integration of categories developed during substantive coding into a hypothesis or theory (Glaser & Strauss, 1998; Walker & Myrick, 2006). Glaser elaborated on concepts such as theoretical sampling, theoretical coding and the use of theoretical memos (Heath & Cowley, 2003). Strauss' method of analysis recommends that the researcher mine the data and select in substantive coding, then uses theoretical coding to relate and integrate into the emerging theory (Walker & Myrick, 2006). The use of constant comparison and circular analysis of the relationship between codes lead to advanced coding and higher levels of theoretical conceptualization that was utilized to develop the theory (Boychuk Duchscher & Morgan, 2004).

Open coding is the first stage of analysis that occurs and is described as an interpretive process in which the data is broken down analytically to provide insights into the phenomena reflected in the data through the use of constant comparison (Corbin & Strauss, 1990). Events, actions, and interactions are compared for similarities and differences and are then given conceptual labels. The category is further broken down into specific properties (characteristics or components) and their dimensions (variations of a property) (Corbin & Strauss, 2008; Corbin & Strauss, 1990). Open coding stimulated generative and comparative questions that served to guide the future work in the field as interviews took place (Corbin & Strauss, 1990).

Finally, selective coding is the process in which all categories are unified around a core category, which represents the central phenomenon of the study (Corbin & Strauss, 1990). Selective coding occurs when previously coded categories become saturated

which allows the researcher to have a sense of the emergent core (Boychuk Duchscher & Morgan, 2004).

#### 4.8. Matrix

The matrix is a tool, which provides a systematic, logical and integrated account of significant events, which encourage the data to provide a picture of what is going in the data (Strauss & Corbin, 1998). The matrix is an analytic device that assists the researcher to identify relationships between the conditions and interactions of the data. It is through this process of analysis that the theory emerges describing the complexity and richness of the life experiences expressed through the data (Strauss & Corbin, 1998). A matrix was developed that emerged from the interviews in assisting in the analysis of the data, see Figure 1 and 2.

#### 4.9. Field Notes

Once each interview was completed, I documented observations and reflections about the interview as well as personal reactions or emotions that arose throughout the process in my field notebook. Corbin & Strauss (2008) speak to the importance of the researcher keeping a journal or field notes throughout the research process as it helps us to be aware of who we are and how we are affected by what we experience. It is vital that researchers be self-reflective about how we influence the research process and how the research process influences us (Corbin & Strauss, 2008). I documented the length and location of the interview, and any information that was relevant to the research question, as well as my personal observations, feelings, and reactions to the interview.

During the process of data analysis, it is recommended that researchers keep written records (or memos) and diagrams of the products of analyses as it progresses

(Corbin & Strauss, 2008). The act of writing or diagramming the emerging theory influenced me to interact with the data in ways that allowed for further analysis and integration to occur. Qualitative analysis involves complex and cumulative thinking, which is difficult to track and retain without the use of memos (Corbin & Strauss, 2008). In addition, the use of memos and diagrams encourages the researcher to work with concepts rather than raw data (Corbin & Strauss, 2008). For these reasons, I utilized memo writing and diagramming throughout the analysis, which assisted in building the theory.

#### 4.10. Trustworthiness

Trustworthiness is the criterion used to describe validity of the qualitative analysis. Lincoln and Guba (1985) suggest that establishing rigor and trustworthiness in qualitative research is dependent upon interpretations developed from the data being faithful to the descriptions of the experiences shared by research participants. I ensured the participants that utilizing a pseudonym would protect their identity. I also established rapport, developed trust and provided participants with a copy of their interview to review and to make changes or additions.

## 5. DATA ANALYSIS

Through the process of coding, breaking down the data into manageable pieces, asking questions about the data and brainstorming, I developed approximately 24 open codes as I read through the 20 transcripts. I placed open codes in the left hand margin of the transcript when I saw a concept or word that reflected one of the coding categories. These open codes were general enough to include broad categories of information that could answer the research question. This process of coding took a tremendous amount of time. Each participant shared their individual life experiences in a very specific way that ultimately resulted in the large amount of open sub-codes. The themes/categories that emerged from the process of coding represents the Aboriginal communities' life experiences of HIV/AIDS.

To complete the process of coding, I developed tools to assist in the process of visualizing the data. For example, I needed the ability to "see" the data, so I proceeded with the coding by highlighting each quotation that related to a specific open code. I then pasted these quotations onto sticky paper and attached them to a number of poster boards as files organized by open code, and color-coded by those affected by (black marker) or those living with (red marker) HIV/AIDS. Then, sitting with the content of each open code, I furthered my analysis and moved to a more abstract level, making notes in my field notebook as the theory developed. I again utilized a poster board to assist with the organization of the codes using color markers to assist in a visual process for analyzing the data. This process was challenging, as there were so many coding categories that were emerging from the data. This step led to the next level of coding, axial coding.

In axial coding I looked to the data to test the relationships between categories (Corbin & Strauss, 1990). The purpose of axial coding is to put the fractured data back together in new ways (Strauss & Corbin, 1990). I first used the “cut and paste” method of cutting around each quotation that related to an open code; I then pasted these quotations into files organized by open codes. Using the constant comparative method, subcategories (files of quotations organized by open codes) emerged to explicate conditions, contexts, strategies and consequences of the emerging theory (Corbin & Strauss, 1998; Walker & Myrick, 2006). Drawing on the references to guide data analysis, I remembered that any hypothetical relationships that are derived through the deductive process of axial coding are considered provisional until verified repeatedly against incoming data (Corbin & Strauss, 1990). The process of axial coding requires the researcher to look for the structure, sequence, conditions, and consequences of identified categories through the use of theoretical sampling (Boychuk (Boychuk Duchscher & Morgan, 2004). During this process, I identified a number of relationships, which ultimately formed themes and sub-themes. This process was effective and allowed for me to see how some subcategories would not result in a theme or subtheme,

At times, I had feelings of being overwhelmed, frustrated, and confused. When this occurred, I did access traditional supports through smudging, traditional healers, and mentors and held numerous sweats during this time to assist me in the dissertation process. At one point in the process, at a sweat in the fall of 2011, I received guidance from my ancestors. The ancestors came into the ceremony and shared with me through the elder that was conducting the ceremony that my current challenges included experiences of discernment. The elder received this messaged from the ancestors and

they did not share the message in her language, as there was not a word in our traditional language for it. However, they repeated the word multiple times through the ceremony and indicated to the elder to share this teaching with me after the sweat. When the sweat was over, the elder called me over to discuss what she was told in the ceremony by my ancestors. I was significantly moved emotionally and felt the strength of their support, and came to a realization that the work I was doing was to continue. That night, I returned home to work on the dissertation and I decided to research the term discernment. The meaning of this word was profound and it provided strength at a time when I needed it most. Merriam-Webster (2005) defined the definition of discernment as follows: “The quality to be able to grasp and comprehend what is obscure.” The message that I received was to continue on with the coding process and believe in the results that were emerging; the ancestors believe I am on the right path. These experiences assisted me in this research process; ultimately I relied on my cultural and spiritual supports as I navigated my way on this journey to discovering the emerging theory.

The next level of coding in the process of data analysis of axial coding led to the development of multiple themes, telling a story of the emerging theory (Strauss & Corbin, 1998). Using the process described above, the categories were merged into themes, which is a higher level of abstraction from open coding. I will discuss these themes in the results chapter of this thesis. Eventually the propositional theory emerged, grounded in participants’ life experience, and answering the research question. Both the core categories and the propositional theory will be presented in the results chapter.

At this stage of coding, I selected out the most relevant quotations that illustrated each theme which lead to the development of the emerging theory.



### 5.1. Development of the Matrix

As the theory emerged, I also discovered a diagrammatic representation of the theory (Strauss & Corbin, 1998). Specifically, the conditional/consequential matrix is described as an analytical device that provides a method for the researcher to keep in mind several analytic points at one time.

In the theory building, I pulled together snapshots of the data to provide a complete picture. This process included pulling together pieces of the puzzle to construct a plausible explanatory framework to describe the participants' experiences (Corbin & Strauss, 2008). As the theory emerged from data analysis, the process of refining occurred, where I identified any gaps in the logic and reworked the areas that emerged as requiring more attention. Following this process, I revisited the field notes and placed my field note comments and thoughts within each category identified throughout the conceptualization process (Corbin & Strauss, 2008). The next stage of theory building included integration, which was the final and more difficult part of doing the analysis. This stage was difficult because I tried to stay close to the participants' grounded experiences and found it difficult to represent the diversity of their experiences into a cohesive theory.

I used poster boards to assist in visually organizing the data into categories by writing on sticky notes that were then arranged on poster boards for emerging open coding categories. Following this process, I identified categories that emerged through axial coding, which assisted in further development of the emerging theory by the identification of developing themes. Finally, the process of selective coding occurred, where the theory emerged from the coding of various categories.

## 5.2. Trustworthiness.

I followed the procedure of “member checking” recommended in the literature to ensure trustworthiness of the data (Malterud, 2001; Lincoln & Guba, 1985). Following the completion of each interview, I transcribed it verbatim. Each transcription was emailed or mailed back to the participant for verification of content and accuracy. Not all of the participants returned their verification of the content. One participant requested an additional interview, and this was added to the transcripts. I also asked each participant if they had a pseudonym that they would like me to use to identify them in the study. In most cases, the participants indicated that I could select a pseudonym for them. I had added this option for them, as I felt that this was a way to encourage the participants to continue with the ownership of their life experiences that they shared with me in this study. I shared a three-page description providing the theory and themes as a summary of the results with participants. In addition, I will provide each participant with a summary of the findings post-defense.

## 6. PARTICIPANTS

### 6.1. Summary of Participants

I have chose to share summaries of their life stories in this chapter prior to sharing results of my analysis. In an effort to honour the participants in this study and convey ways in which I saw them to be strong, unique, powerful individuals, I selected pseudonyms. Not all of the participants decided choose their own pseudonyms, as suggested at the time of the interview. I chose most participants pseudonyms from an Aboriginal names website. I selected names from this website that fit each individual in this research. As a researcher and Aboriginal woman, I was deeply touched by the stories shared by participants and wish to honour each one. I anonymized identifying information, except when it seemed essential for the reader to understand my emerging theory (See Table 1).

Table 1 – Participants Demographics

<i>Pseudonym</i>	<i>Age</i>	<i>Identify as Aboriginal</i>	<i>First Nation/ Métis locale</i>	<i>Highest Level of Education</i>	<i>HIV/AIDS Diagnosis (APHA) or Affected by HIV</i>	<i>Receive Service from an AIDS Service organization (ASO)</i>	<i>Relationship Status/ Children</i>	<i>Location of Interview in Canada</i>	<i>Sexual Orientation</i>
Awan (Somebody)	35	Yes	Montana First Nation	Grade 12 1 year post-secondary	APHA	Yes	Single/ No children	Toronto, Ontario	Two-spirited male
Aponi (Butterfly)	40	Yes	Kahkewistahaw First Nation	Grade 12	Affected	Yes	Single/ 6 children	Regina, Sask	Heterosexual female
Citali (Star)	38	Yes	Adopted – Identify with Cree background	Grade 12 Some post-secondary	APHA	Yes	Single/ No children	Toronto, Ontario	Two-spirited male
Donoma (sight of the sun)	39	Yes	Piegan First Nation	Some High school/Life skills coach/PI and Co PI on some research projects	APHA	Yes	Single/ 6 children	Victoria, B.C.	Heterosexual female
Elsu (Flying Falcon)	52	Yes	Tall Cree First Nation	Grade 12 Some post-secondary	APHA	Yes	Married/ No children	Vancouver, B.C.	Two-spirited male
Esarosa (Whitewolf)	59	Yes	Métis	Grade 12 Some post-secondary	APHA	Yes	Common-law	Windsor, Ontario	Two-spirited male
Guitan (Heart of Young Wolf)	60	Yes	Métis	Some high school Some post-secondary	APHA	Yes	Divorced/ 2 children	Windsor, Ontario	Two-spirited male
Huyana (Falling rain)	29	Yes	Peepeekisis First Nation	Grade 9-10 Life skills training	APHA	Yes	Single/ 3 children	Regina, Sask	Heterosexual female
Iniabi (the sun which all life depends on)	42	Yes	Adopted – Identify with being First Nation	Grade 12 Some certification training	APHA	Yes	Single/ No children	Toronto, Ontario	Two-spirited male
Jacy (the moon)	37	Yes	Nakazalli First Nation	Grade 11 Some college,	APHA	Yes	Single/ 3 children	Prince George,	Heterosexual

Kachine (sacred dancer)	56	Yes	MikMaq/ Black/Métis	certification training Grade 12	Affected	Yes	Single/ No children	B.C. Nova Scotia	female Heterosexual female
Lakota (Friend)	51	Yes	Mohawk	Some high school	APHA	No	Single/ 1 child	Oka, Quebec/ Ontario	Heterosexual male
Makya (The Eagle Hunter)	46	Yes	Pasqua First Nation	Grade 12	APHA	Yes	Single/ No children	Vancouver, B.C.	Two-spirited male
Namid (a dancer)	29	Yes	Sakimay First Nation	Grade 12 Some post-secondary	Affected	No	Single/ 1 child	Regina, Sask	Heterosexual female
Onida (expected or awaiting)	25	Yes	George Gordon First Nation	Grade 12 Some post-secondary	Affected	No	Single/ No children	Regina, Sask	Heterosexual male
Paco (gold eagle)	46	Yes	Sandy Beach/Paul First Nation	Grade 12 2 years post-secondary	Affected	Yes	Single/ 5 children	Sandy Beach, Alberta	Heterosexual female
Satinika (Magic Dancer)	49	Yes	Opaskwayak Cross lake First Nation	Grade 12	APHA	Yes	Single/ No children	Winnipeg, Manitoba	Two-spirited male
Takoda (friend of all)	44	Yes	Muskoday First Nation	Some high school	APHA	Yes	Single/ 6 children	Prince Albert, Sask	Heterosexual female
Wapeka (Skillful)	38	Yes	Whitecap Dakota First Nation	Some high school	APHA	Yes	Common-law/ 1 child	Winnipeg, Manitoba	Heterosexual male
Yotin (wind)	35	Yes	Beardy's Okemasis First Nation	Some high school	Affected	No	Single/ No children	Saskatoon, Sask	Heterosexual female

### 6.1.1. Awan (Somebody)

*“I am an AIDS advocate, I go out speaking, that’s what I do, I go around speaking. Put information out there, so that it is not so scary”*

Awan is thirty-six years old, First Nations status and two spirited. He has been living with HIV for over four years, so falls within the “infected” category of my participant sample. Awan described being adopted by a relative of his biological mother soon after he was born. His biological mother was not able to take care of him, as she was living with addictions at the time of his birth. Ultimately AIDS took her life when he was fifteen years old. He has fourteen siblings; six from his mother’s side of the family and nine from his father’s side of the family. He lives three provinces away from his family and may visit when he is traveling through the western prairie province of his birth for speaking engagements, or for family gatherings. Awan indicated that he knew at a young age that he was gay. He stated that he experienced stigma from his family and community members when they learned he was gay. Awan described his First Nation community as not accepting anyone who was gay, which resulted in stigmatization for gay people in this community. He indicated that he does not understand why other gay First Nations men and women stay in that community. The resulting stigmatization within his own community was one of the main reasons why he moved away to Toronto. He stated that he currently feels very connected, accepted and does not experience stigma where he lives, in a larger eastern city.

Awan stated that when he was growing up, he was adopted and raised by his extended family on a Montana First Nation. His family values and his identity were developed with inclusion of cultural/traditional teachings as well as having religion as a

foundation for the family's morals and values. However, he described having to make a choice at a young age whether he would like to learn the traditional ways of sweating, ceremonies with his father, or to attend church with his grandmother. He chose to attend the Church services with his grandmother and described this choice as a child as resulting in currently being disconnected from the traditional teachings and ceremonies. Although, he indicated he is open to utilizing some of the cultural/traditional aspects available through supports and services where he lives, such as sharing circles, smudging and the use of eagle feathers.

Awan learned of his HIV positive diagnosis when he attended an HIV anonymous testing site in Toronto, Ontario. He stated that the diagnosis "came as a shock to me". He stated that learning his diagnosis has increased feelings of anxiety and at times results in depression. He indicated that HIV has also had a negative influence on his sleep. He described having been diagnosed with a sleeping disorder, which he feels is directly related to the HIV diagnosis. He has accessed numerous supports and services to address his sleep disorder, including doctors sleep clinics. However, he reported that so far nothing has worked to assist him and he does not have a lot of hope to be able to sleep at night. Awan currently takes sleeping medication to help him to get some rest at night. He indicated that he has not had a good night's rest since his diagnosis, over four years ago. His sleep consists of approximately three hours a night.

Currently, Awan adheres to prescribed HIV medication regimen (consisting of 18-19 pills a day) that assists him to function physically day to day. He indicated that the regime is physically draining and has ultimately been responsible for the lack of energy that he feels, but without the medications, he knows that his viral load will not improve.

He stated that he is an active speaker in HIV/AIDS, trans and two-spirited communities. He has been speaking about his journey living with HIV/AIDS for over three years. He shares his life experiences as a way of educating others who do not know about the illness. “Probably just show them the pills and everything. Show them the dangers and I don’t know, like somebody didn’t tell me. Somebody might not tell you.” He believes that the speaking that he does has an impact on incidence of illness and he hopes it will prevent others from having to experience HIV/AIDS.

#### 6.1.2. Aponi (Butterfly)

*“We need to start opening our minds, our hearts, and just reconnecting with that, our elders teach us that. It’s a cycle you know and we need to, that’s the one thing that we don’t want to deal with is the emotions.”*

Aponi is a forty one year old First Nation status woman from Kahkewistahaw First Nation. She indicated that she has been affected by HIV/AIDS since 1996. She described living with an unhealthy lifestyle that included being addicted to drugs, being in an abusive relationship and being exposed daily to high-risk addiction situations. Recently, her brother was diagnosed with HIV and she indicated that her family has experienced a lot of emotional challenges when they learned of his APHA diagnosis. Aponi is the mother of six children ranging in ages 24 to 4. Currently, her children do not live with her, which is the direct result of her previous drug addiction. She does have consistent contact with them and stated that they have adapted well to their living situations. She reported that one day she hopes to become a full time mother again.

Aponi described growing up in residential schools and foster care. She indicated that it was difficult being away from her family, as well as experiencing being treated like



an outsider. “Being raised in foster care and you know being put out in residential school and on the reserve, you know. I’m pretty much, did not feel accepted on my reserve, I don’t know for me I always felt picked on by [two neighboring First Nations].” She describes that since being sober, relationships with her communities and her family have strengthened. She indicated that when her brother was diagnosed, her dad and most of the family did not want to be around her brother due to the stigma they had towards HIV and because he has a diagnosed mental illness. Over the past few years, she indicated that it has taken time and effort to provide connections within her family, to address the stigma her brother experiences. She stated that recently, her dad began to be open and willing to learn about the illness and she stated that she gathers pamphlets and information to share with her family to assist them to become educated about HIV/AIDS.

Aponi described that she has been involved in the journey of HIV/AIDS more than fifteen years. She indicated that she began feeling affected by HIV while she was in a nearby province and living a life of addictions and violence. She acknowledged that she has come a long way since that time and stated that she was really lucky to have walked away from that life without being infected herself. She reported that her partner at the time injected her, as she did not know how, and was afraid of needles. She also stated that at that time during her addictions, she did not have control over the needles that were used on her body. Numerous times she felt she could have been exposed to the virus, as she did live a risky addiction lifestyle. She currently lives in an Aboriginal AIDS Service Organization (AASO) apartment where most of her neighbors are living positive with HIV. She also works at an Aboriginal AIDS Service Organization (AASO); she began this work after she started living her life free from addictions. Aponi took part in a focus

group when she was starting on her journey of healing and this is how she became involved in volunteering and eventually working with the AASO. She has been free from drugs and alcohol for over two years and continues to work at the AASO.

### 6.1.3. Citlali (Star)

*“You know. People used to be always closeted in any kind of personal feelings and stuff like that. It’s good to see that they are having groups for that. And there is a lot of backing from them too.”*

Citlali is thirty-eight years old, Cree, First Nations status and two spirited. He described living with HIV for over ten years. He reported that a “white family” who lived in Ontario, adopted him when he was two and a half years old. He described being loved by his adopted family, where he was the youngest of four adopted children, from different families. He stated that when he decided to “come out” to his family, it was a very difficult time. He stated that he had been raised with a strong foundation of trust and respect; this strong emotional foundation was the direct result of how his parents raised him. This foundation included giving him ways to express himself emotionally, in a healthy way. This environment of trust encouraged him to learn how to express his emotions and feelings. However, he described some difficult emotional challenges, such as, the entire family not accepting him as two-spirited. The results of him coming out to his family was that most of his siblings did not have any contact with him in over twenty years; he described them as: “not supportive in any of that whatsoever. Like there’s shame.” However, he continues to hope that one day they may be able to open their lives to him again. Until then, he attempts to contact them from time to time to build a relationship with them.

Citlali has not met his biological family and stated that all he knows is that he is originally from a First Nation in a western province. He learned this when he applied for his treaty status when he turned eighteen years old. He described searching for his biological family because he was interested in learning more about his background. Specifically, he was interested in learning about health, diseases, etc. He continues to search for this information and hopes that one day he will know more about his personal history and background.

Citlali described being affected by HIV for over twenty years and living positive with HIV for the past ten. He stated that when he learned his best friend was APHA, he experienced some trauma. He described that he had known her for over twenty years and knew she was injecting drugs. She was his best friend and she was a Transgendered woman, who had been through many struggles with him. It was difficult dealing with the emotions that accompanied her diagnosis as, at that time, the medications were not as effective as they are today. He knew she would likely pass away. At that time, he described becoming emotionally drained because HIV was affecting him. He stated that she was the first of many friends who were infected with HIV within his community. He described the emotional trauma being linked to the fact that he had lost many friends to the illness; these friends have since died. Citlali stated that at times, he continues to be overwhelmed with emotions and seeks support to assist in dealing with these feelings.

Citlali often attends AIDS Service Organizations (ASO) s and AASO's in the Toronto area and stated that people in these organizations are very accepting of two-spirited and trans individuals. He described feeling connected to Aboriginal culture and traditions. He indicated that he has built a strong cultural and traditional background, and

that he accesses supports from Elders, and attends sweats and powwows. Citlali described wanting to learn more about Aboriginal traditions and culture as they have assisted in his healing journey. He described feeling empowered by the supports: “I have a couple of elders that I see on a regular basis. Then I usually confide in [them] if I am having a rough time or usually, you know we talk it out. And we have our little spiritual circle and sweet grass and all of that kind of stuff.” He indicated that he feels accepted in his community for who he is and stated that these supports have been the foundation from which he has developed his strengths.

#### 6.1.4. Donoma (Sight of the Sun)

*“... from my family. My mom’s side of the family and other people from back home treated me the same. I think there was, you know, obvious fear and curiosity and ignorance. But it wasn’t beyond anything that we could handle. Like my family got educated and tried to learn as much as they could; and tried to be there.”*

Donoma is a forty-year-old First Nations status woman from Piikanni First Nation and Kwa’Kwa’Ka Wakw’. She described living with HIV for over twenty-two years. She started living on the streets of Vancouver when she was fifteen years old. Donoma is the mother of an eighteen-year-old daughter and a nine-year-old son and has been in a common law relationship for the past two years. Currently, she is an advocate in the fight against HIV/AIDS. She has been active in the movement for almost two decades. She moved back home to be close to family once she decided she was through with the drugs and the street life. She met a medical doctor, who specialized in HIV/AIDS. He invited her to join him traveling to communities in Canada and the United States, to share her life experience of living HIV positive. She acknowledged that if she did not have the support

of her family, extended family and friends behind her, she might not have been able to speak out publicly about the illness.

Donoma stated that as a child she moved around a lot, from home to home within her mother's First Nation community. She described living there for two years, from ages four to six. Her mother made the decision to move her away from the community because she reported that the teacher in her school was hitting the children. She moved in with her grandparents who lived in Victoria until grade eight. She then moved back to her mother's community. When she returned, she recognized that she was experiencing symptoms of mental illness and began to feel symptoms of depression. She described the depression as being related to the multiple traumas and abuses that she had suffered throughout her childhood and teens. At this time numerous community members were sharing their experiences of being sexually and physically abused. She recalled that one year there had been approximately forty-five deaths in the community. She stated that these deaths resulted from abuses that the community members suffered. She said, "many community members were falling into despair and killing themselves." This was when Donoma decided that she was ready to leave her community behind, and thought she would escape her pain by getting out of there. Soon after her decision to move away to Vancouver, she became a ward of the courts, where she described, "once I got into the child welfare system, I kind of bounced around. I didn't finish high school, started hanging around on Hastings Street." At that time, her life was spent on the street of Vancouver, in an effort to escape her feelings of abuse and abandonment she became filled with a life of addictions and prostitution.

Donoma has been active in the HIV/AIDS movement for over twenty years. She started in this work because she felt that it was a part of her journey with HIV to assist others by sharing her life experiences. She stated that communities related to her because she was a young First Nations woman, and they felt connected to her. She described traveling with a well-known doctor throughout B.C.; it felt like a whirlwind throughout the province, as once they presented in one community, they would be invited to the next and so on. She described that once she disclosed her HIV positive status her life changed. She reported that she experienced a positive emotional change when she started on this journey of sharing her story. She indicated that at one point, she felt that her life was going to end soon and that this was her way to assist in saving one person. The presentations included educational information about the illness in order to assist in prevention. She described that at first she would go and talk to the communities, tell her story and provide basic HIV information. Eventually, she participated in a video about her life experiences of being First Nations, a mother and living HIV positive; this video was distributed widely across Canada. The video has had a positive impact and ultimately has assisted in educating thousands of people across Canada and the United States.

#### 6.1.5. Elsu (Flying Falcon)

*“We don’t have counselors, we don’t have psychiatrists, we don’t have any support mechanisms for our families, our partners, because, I mean, I know there are Aboriginal, we do have Aboriginal psychiatrists and counselors out there, but we are not being able to tap into that, for some reason, which is one of the number one things.”*

Elsu is a fifty two year old First Nations status, gay/two-spirited man from Tall Cree First Nation. He described being affected by HIV since 1985 when the epidemic

emerged. He has been living APHA for the past fifteen years. He has been common law married to his partner for over nineteen years; they raise two cats together. He is active on numerous committees that are linked to ASOs and ASSOs. He is an advocate for Aboriginal people who are APHA and assists them in challenges within the system when accessing supports and treatments for HIV. He described numerous barriers and challenges that Aboriginal peoples face when living with HIV. He believes they are directly linked to the poverty, lack of support and services that are not being provided in the large urban city that he currently resides in. He indicated that he has taken on these challenges as an advocate and hopes that one day he will be able to make a policy change and improve the health, support and services for APHA people.

Elsu described the importance of the old people, the elders, in Aboriginal communities and their significant abilities to communicate and educate. He indicated that historically, the elders would sit with the community members and share their teachings about life. He acknowledged that currently Aboriginal communities face challenges in communication and education because he stated that traditional ways of teaching have changed, as community members have moved from their rural homes and are displaced in large cities. "Like living in the city, how do you get other APHAs together and just have, you know, put a meal out and just talk?" Elsu stated that some of the barriers to creating a gathering were linked to transportation, funding and location. He stated that he does not give up easily and will continue to work towards improving the services and supports for APHAs. He has been an advocate for over twenty years and at times he has witnessed policy change. He stated he would persist in addressing the challenges as they arise until services and supports meet the needs for APHAs.

Elsu was raised in the foster care system in British Columbia. He recalled being the only Aboriginal kid in the community he was raised in. This resulted in him creating an identity that felt like he did not belong as a child; this identity followed him into his early adult years. He has met a few biological family members over the years and stated that they did not connect. He currently has a strong identity, and his extended family members support him unconditionally. His circles of friends are made up of extended family members who are mostly gay/two-spirited.

#### 6.1.6. Esarosa (White Wolf)

*“And like I feel great! You know, I’ve got energy. I am up at five in the morning, I look around my house, I put some tobacco out and I say Creator, I am yours. What do I need to do here today. It’s almost like it guides me.”*

Esarosa is a fifty eight year old, Métis, Blackfoot Nation and two-spirited man. He described living APHA for over twenty-one years. He has been common law married to his partner for over twenty years. They raised his partner’s two sons together, since they were aged three and four years old, in a rural location in Ontario. He described having a supportive family who assisted him on his journey of living APHA. He indicated that it was not always a supportive environment and that his family members have come a long way from the onset of the illness. For example, his father did not agree with Esarosa’s lifestyle choices, specifically in regards to being a two-spirited man. Esarosa had been married to a woman prior to living with his current partner. In “those” days, most men who were gay lived life on the “down low” and remained in the closet with their sexuality. Although, he and his partner decided they were in love and were going to live life as they felt they needed to, openly. He described that in time, his partner



and dad became good friends. His father came to accept him for who he was and he now surrounds himself with supportive friends who also accept him as he is.

Esarosa identified that he has a strong connection to his First Nations traditional, spiritual and cultural teachings. He described having a medicine wheel garden he designed and created on his land at his home, where he gains strength. This connection to traditional healing emerged for him, as he developed his identity as a healer. He believes in wholistic health and combines western and traditional medicines to assist in his APHA care. He stated that having traditional supports assists him in his daily functioning and assists him to be a whole person.

Esarosa has a large family, consisting of twenty-seven siblings. He described that out of the family, he has relationships with three individuals. These siblings understand him and are open to learning and understanding about HIV. He described that his grandparents had a strong impact on who he is today. He described learning about the lessons that they taught him over the past number of years. He indicated that he did not pay much attention to these teachings at the time. However, as he ages he realizes they had rich information to share and it is time to learn about the lessons. For example, he described one of his grandmothers as always putting aside a plate for the ancestors. He indicated that at the time, he was not clear why she did this. Recently, he learned that the plate was to honour those ancestors that had passed away. He acknowledged that the growing he is currently doing will continue to assist him on his journey to feel good about himself, build his self-esteem and help him continue to becoming a healthier individual.

#### 6.1.7. Guitain (Heart of Young Wolf)

*“Finding out that I was HIV positive and being... it opened my whole, it started me to find the Red Road because there is not room in Christianity for homosexuality. And I’ve spent my whole life busting out of boxes that other people have foolishly tried to put me in.”*

Guitan is a fifty three year old, Cree and two-spirited man. He described being affected by HIV for over twenty years as well as living APHA for over eighteen years. He is divorced from his wife and has been common law married to his partner for over twenty years. He has two sons aged twenty-one and twenty-five from his first marriage. He and his partner currently live in a rural location in Ontario. He described his biological family being disconnected and not supportive of his APHA status. Guitan described building an extended family within the gay community and this has provided support to him unconditional. He stated that when a person is not accepted because of their sexuality and experiences discrimination by their own relatives, they learn to build their own families. He indicated that in his experience within the gay community, they embrace you as who you are, without judgments. He has numerous supports who he described as being his extended family members.

Guitan described the importance of having people who are living positive with HIV as the front line supports in servicing agencies. He stated “it is easier to teach office skills than it is to teach someone how it feels to live with AIDS and thrive.” He described that he would prefer to walk into an ASO/agency for services and support and see someone at the reception that is a PHA/APHA. He indicated that there is a level of respect and understanding that they have, that you cannot have when one is not an APHA/APAA. He suggested that First Nations communities invest in their community

members who are APHAs and build capacity within, by hiring those APHAs to work in health positions so they can support and educate community members on reserve. He stated this would also assist people to understand that many APHAs want to work and live within their First Nations communities.

Guitan described the importance of Aboriginal spirituality and culture as a part of the healing process when learning to accept and live with his APHA diagnosis. He stated that one of the most important teachings he received was learning about his culture, and how being two-spirited was always a part of the teachings. Once he learned this he felt a strong connection to his Aboriginal background and teachings. He described growing up with Christianity in his immediate family; because of these teachings, he was raised under the impression that homosexuality was wrong. However, he learned that being Two-spirited was not only acceptable; it was also thought of as being an honour within his community. He described culture and spirituality as being directly associated with his healing journey. Guitan indicated that the connection to culture and spirituality was the main reason he was able to accept his APHA diagnosis. He stated that for the first ten years of his diagnosis, he was disconnected from himself and it was a challenge to live each day at that time. With his renewed connection to spirit, he described living life without concerns, as his strength emerges from culture and spirituality within his First Nations teachings. He currently provides support in forms of medicine wheel teachings, sharing circles and connection to Mother Earth.

#### 6.1.8. Huyana (Falling Rain)

*“We need to just accept that HIV, just accept it, not like, oh it’s here, just to accept it and acknowledge it. That, you know what, each and every one of us as an Aboriginal person today is either infected or affected directly, from HIV/AIDS.”*

Huyana is a 29 year old, First Nations status woman from Peepeekeesis First Nation. She has been living APHA for over seven years. She is the mother of three children, two of whom she carried while HIV +. Her children range from the ages twelve to one and a half. She indicated that they are not APHA and she followed prenatal protocol with medications while pregnant with them. She is currently in a relationship with a boyfriend, whom she has a child with. She described experiencing stigma and discrimination within the health care field when she was pregnant with her children. She stated that the doctors have often advised her to tie her tubes when she attended doctors’ appointments while pregnant. She indicated that they would challenge and question why she would get pregnant while being APHA. She stated that she and her partner understood that there would be risks and chose to become parents. She and her partner believe that society should not have a say about whether she decides to have children or not. She indicated that she loves her children and is a great mother, which is all that should matter.

Huyana is active as an advocate provincially and nationally for APHAs. She spends much of her time educating and creating awareness about HIV/AIDS within Aboriginal and non-Aboriginal communities. She indicated that this work comes with challenges and some rewards. Although, she mentioned that there are some First Nations communities that are not ready to hear her story and she mentioned that there are so many misconceptions about the illness. For example, recently she was educating on reserve,

and one of the youth there was being very disrespectful about the content of her presentation. He stated that you can get HIV from a toilet seat. She challenged the youth and he responded rudely. She stated that in her experience, children do not have the respect that they used to have and this is a barrier when educating on reserve youth. However, she described persevering through the challenges; she stated that if her story can influence one youth to make informed and educated choices with sexual health, then she has done what she set out to do.

Huyana described that supports for HIV/AIDS should include culture and tradition when working with Aboriginal communities, as it helps to balance a person's life holistically. She indicated that she would not be here today if she did not have the connection to traditional and cultural supports. She approaches elders for support and guidance, participates in sweats, sharing circles and accesses traditional medicines; these assist with her connecting to culture and at times assist with the side effects of western medications.

#### 6.1.9. Iniabi (The Sun on Which All Life Depends)

*"I've done a lot of work on myself, I am aware and people have been more like, there should be a guideline of people being more self-aware, of you know, who they are now. As opposed to who they were before and try and celebrate some of the good from before to now. And you know, look at it like; okay, things aren't as bad as they are."*

Iniabi is a forty three year old, First Nations status two-spirited man who was adopted as a child, raised with other adopted siblings and three of his adopted parents' biological children. He described not being sure of which First Nation he belongs to in Canada. He recently decided that he would like to learn more about where he is originally

from and has started the process of locating his adoption forms that indicate what First Nation he belongs to. A reason for this is because he wants to learn more about his health background. He has been living APHA for over thirteen years. He is currently single after being in an unhealthy relationship with a man for over ten years. He described being an intimate partner violence survivor for the past few years. He decided that he was going to leave the relationship when he learned he was HIV positive. He indicated that his partner at the time raped him and this is how he believes that he contracted the HIV/virus. He stated that he has anger over this today and is still working on forgiving his ex-partner for this trauma.

Iniabi described that he experienced drug and alcohol abuse in his life. At times, he indicated that he might have used drugs and alcohol to bury the pain that he experienced and was not ready to cope with. Although, over time, he has noticed that he is on a healing journey where he is becoming more aware and is engaged in understanding the feelings that he has in regards to the traumas he experienced in his life. He stated that his roommates provide him with unconditional support and that they do not judge him. He stated that in the past he was very secretive about his life and the trauma that he experienced. He stated that he used to lack the ability to feel and had been clinically depressed for over three years.

Iniabi indicated that he relies heavily on his ability to focus on his self-care and alternative methods of healing for HIV/AIDS. He accesses eastern medicine, naturopaths, does yoga and acupuncture. He stated that these methods of holistic and alternative health options have assisted him to become a healthier person, who is an APHA. He also suggested that using alternative methods to HIV medications has empowered him in his

healing in mind, body and soul. He indicated that he feels that he has control over how he will cope with his illness. He does not want to become a burden on anyone because he is HIV/AIDS positive.

#### 6.1.10. Jacy (The Moon)

*“Mom, you want to add something? Yes, the elders. She said it is all about the elders. My mom is 70 years old. She’s the elder in our family now. She’s the head, she’s the matriarch. There is no one older than her in our entire family. And she’s really well educated about HIV/AIDS.”*

Jacy is a thirty nine year old, First Nations status woman who is an APHA for over nine years. She has a younger brother who is also HIV positive. She is a single mother of three children that range from age 20 to 15. She described experiencing depression when she learned that she was HIV positive. She also struggled with alcohol and drug abuse at the onset of the illness. Over time, she has become a strong advocate in Aboriginal and non-Aboriginal HIV/AIDS communities. She described one of the challenges that she is currently facing is the lack of programs that are offered for children who are affected by HIV/AIDS. She indicated that her children would benefit from services and supports in regards to HIV/AIDS, as they also experience emotional trauma when they learn their parent is ill. In the western province where she lives, there is a provincial camp that is available for youth. However, her children left camp early, as it was what she described as being “culturally inappropriate”.

Jacy was raised by her mother in her First Nations community in the north, with several siblings. She described her life as living off the land and the animals on the land. That traditional way of life is strong in her community. Much has changed in regards to

the ability to cope, or more specifically, not to cope with the multiple traumas that many First Nations community members will experience. Her children have been raised in a community where HIV affects every family in their northern community. She stated that there are generational effects of broken families and this is directly related to why her community is experiencing epidemic proportions of HIV/AIDS. Jacy indicated that this has resulted from the generational traumas that her community has experienced. Effects of physical and emotional abuses have direct implications for why her community members drown in addictions. She reported that it is time for the healing to begin and for programs and services to assist in the addiction and abuse issues.

Jacy is supported unconditionally by her mother, and described her mother as being her closest confidant. She reported that the First Nations children in her First Nations community do not have their needs met because of the limitations of their parenting abilities within her community, and indicates that this is the direct result of residential schools. She stated that it is urgent to start a support program that will provide the youth in her community a safe place to go when they cannot go home. She reported that with the majority of community members abusing drugs and alcohol, children are the victims, affected by the risky lifestyles. It is time for the generational abuses to stop and for the children to have a safe place to be. At the time of this interview, Jacy had six kids from the community ‘camping’ on her floor because they feel safe there. She stated that if this service was provided in their community to all youth, this would assist in the reduction of HIV/AIDs in her community.

6.1.11. Kachine (Sacred Dancer)



*“My brother, the two-spirited man, you know. He had not embraced our identity, as mixed, Aboriginal. He wasn’t drawn to be a part of the community. He fully supported me, which I was grateful for.”*

Kachine is a fifty five year old, Aboriginal Black/Mikmaq woman who has been affected by HIV for over eighteen years. She described that she has not often spoken about her brother’s illness and this is the first time she has shared her experience of being affected by HIV/AIDs. She had a twin brother who was HIV/AIDs positive and died of complications due to AIDS in 1995. She and her twin brother were raised together in foster care until the age of thirteen, when their foster parents died suddenly. At this time, they were reunited with their biological mother and lived in a large city in eastern Canada. She described that both she and her brother experienced a lot of challenges in their lives after the death of their foster parents. As well, she indicated that their childhood was marked by emotional and physical abuses, and that they both coped with these issues in different ways.

Kachine has followed a spiritual/traditional healing path that includes becoming a traditional healer and pipe carrier. She indicated that she has come a long way in her training, as she becomes stronger in her healing and spiritual knowledge. Kachine described that she knew she had a gift but was unsure of how to utilize it. She described learning more by gaining a connection back to her peoples, in Mikmaq territories. Soon after she followed the trail of where her peoples came from, she became a carrier of a sacred bundle. She was chosen by her ancestors to carry this bundle and she described that it is her role to continue to learn and share the sacred teachings and knowledge.

She reported that she and her twin brother went in different directions when they were searching for their identities. She reported that he chose a path of risky lifestyle that was riddled with fast pace and hard life. She indicated that she had also had a hard life, where she felt she did not belong. She reported that she had experienced mental health issues and attended appointments with a psychiatrist for over three years. However, when the psychiatrist referred her for further treatment in an inpatient facility, she felt she had enough. She decided that she would find a way to cope with the sorrow and the pain outside of the western stream and focused her energy on finding out why she was in so much pain. This journey led her to gain insight into her connection to spirituality and led her to the wholistic health model that she follows today. She reported that at the time she did not know that she would be a sacred bundle carrier. She stated that today, being connected to her culture has assisted her to deal with the emotional pain that she had been suffering for years.

#### 6.1.12. Lakota (Friend)

*“I’ve been using the clinic for almost 27 years now; they don’t know what to make of it. Every time I go in there, they smile. I have nothing to hide, nothing to lose. I have the whole world to gain.”*

Lakota is a fifty-two years old, First Nations Status man from Oka/Kanesatake First Nation who has been living with HIV for over twenty-five years. He has an ex-wife who experienced a pregnancy while he was HIV positive, over 20 years ago. His daughter was born healthy and is a beautiful young lady today. He stated that he learned he was HIV positive from his doctor. He indicated that he had been going through numerous surgeries, where he required blood and was a recipient of the “tainted” blood.

A blood test revealed that he was HIV and Hepatitis C positive. At the time that his doctor delivered this news to Lakota, the doctor also stated that he would have less than five years to live. He indicated that this news was a lot to deal with emotionally and he decided to live a fast hard life, do everything he could think of on his bucket list, if in fact he had five years to live.

Lakota indicated that he had a tremendously hard time dealing with his HIV positive diagnosis. He reported that he attempted to take his life approximately seven times using various methods. He reported that he decided to live a risky lifestyle without much regard for the future. Lakota stated that if his mother had not found a clinical trial for HIV/AIDS in the 1990's, he might have ended his life. When he signed up for the trial, he stated that the doctor in charge of the trial was an infectious disease specialist. The participation in this trial changed the momentum of his life from risky to living a healthier lifestyle.

Lakota is an advocate and speaker for HIV/AIDS within the Aboriginal community. He described his strongest supporter as his mother, who has always been there for him. He indicates that his sister and brother are also supportive to him, although they did not know how to discuss the illness with him until recently. He stated it is important for him to have a connection to cultural and spiritual supports. He indicated that since his diagnosis came as such a shock, it has taken decades to come to terms with the illness. He credits where he is today as being connected to the supports he received from his family, extended family and holistic supports.

6.1.13. Makya (The Eagle Hunter)

*“And the reason why I kept that to myself was because I never talked about my feelings. You know that’s why I kept it to myself because I did not know how to talk about my feelings. I really didn’t know that you were supposed to talk about your feelings (He laughs).”*

Makya is a forty-seven years old, First Nations Status two-spirited man from Pasqua First Nation who has been living with HIV for over twenty-six years. He stated that he knew he was sick prior to the diagnosis, although he was not sure what he had. He indicated that when he was diagnosed; he was AIDS positive and must have had HIV for many years prior to the AIDS diagnosis. He indicated that he experienced numerous emotions, such as fear and the potential that he may die soon. He reported that he had avoided the emotional turmoil by relying on alcohol and drugs to numb his pain. He indicated that he was “out of my mind” for over four years in a spiral of addictions. Since that time, he described that he has walked on the path of sobriety and reported that this has assisted him to live a fuller and healthier life.

Makya was raised by his mother for part of his childhood and has two siblings. He described living in residential school for part of his childhood, where he was abused physically, sexually and emotionally. He described not dealing with the emotional trauma from those abuses and relied on alcohol and drugs to ease the pain. He reported that his mother provided him with unconditional love and support. He stated that his siblings also struggle with addictions. He stated that his mother is one of the reasons why he is still here today, as she supported him unconditionally and was there for him through all the good times and the bad.

Makya stated that seeking supports once he was ready to deal with his emotional trauma, was difficult. He indicated that for him to reach out for help was not an easy task. He stated that fear and shame almost prevented him from seeking the supports and services he received from AIDS Vancouver and PWA, as he could not bear to walk in the door to seek their services. However, he realized that it was time to start on his path to healing, and he did walk in their doors for supports. He stated that he was scared when he walked in the door. However, he indicated that soon he realized that he was amongst friends and acquaintances that he had seen around the East side. He described facing his fear as being an empowering experience for him to seek the supports and services.

#### 6.1.14. Namid (A Dancer)

*“My mother contracted HIV when I was younger. And I found out that she had HIV and I really didn’t know how to handle it at first. I really didn’t know anything about it. I just knew my mom was sick. It was really hard to deal with growing up.”*

Namid is a twenty nine years old, First Nations status woman from Sakimay First Nation who was affected by HIV for over twenty-two years. She is the mother of a daughter. Namid’s mother was diagnosed with HIV in the late eighties and passed away while living AIDS positive on the east side of Vancouver in the mid-nineties. She stated that she knew her mother was sick but she was not sure what HIV was, as no one educated her about this illness. She described being told by social workers and foster parents that her mother was sick. She stated as a child that she often wondered what illness her mother had that made her sick and how she help her mother get well. She recalled the times with her mother as being some of the best memories she had of her childhood, as her mother was loving, caring and provided much comfort.

Namid indicated that when she learned that her mother had HIV, it directly related to negative effects on her life. She indicated that she carried a lot of emotional pain, hurt and anger. She reported that her auntie decided to tell her when she was 13 what her mother was sick from. She reported that when she learned that her mother was HIV positive, her life changed. She indicated that she experienced tremendous stigma and discrimination from people when they learned her mother's diagnosis. She stated that when she was in her teen years, many youth would hold the HIV diagnosis against her in a negative way, which resulted in feelings of shame, and anger. Although, as she matured, she described that she sought to understand the illness better, by seeking educational resources and support. Although, the impact of the emotional trauma from the HIV diagnosis lead her into a brief life of addictions herself.

Namid described that she is comfortable talking about her mother's HIV diagnosis today as she has come a long way from the feelings of fear and shame. She reported that currently, she shares her experiences of being affected with other First Nations young men and women in an effort to educate and create awareness. She described that the more that she can share about HIV/AIDS, the more it will assist in reducing the rates of infections with the prairie province that she currently resides in. She stated that the healing from the stigma, shame and pain as a young woman has resulted in a passion for her to being an advocate for others who have been affected by HIV.

6.1.15. Onida (Expected or Awaiting)

*“Growing up I was seeing it all. I watched them do needles and all of that. So I guess she's had, she got HIV, probably like six years ago. But before that she kind of had problems. We always knew that she had a real drug problem.”*

Onida is a twenty-four years old, First Nations status man from George Gordon First Nation who has been affected by HIV for over six years. His sister was diagnosed with HIV in 2005. He stated that his sister is an injection drug user and lives a risky lifestyle. He indicated that his sister has six children and had two pregnancies while being HIV positive. One of her children, his niece, was diagnosed as HIV positive from birth. He stated that his sister has had a challenging life including domestic violence, addictions and multiple traumas. He described her as being disconnected from the children and fully immersed in the high-risk lifestyle of injection drug use. He stated that their family fully supports his sister's children unconditionally. He stated that family and extended family currently raise the children.

Onida stated that injection drug use was a part of the family, as numerous members use drugs. He indicated that he would not be where he is today without the support of both parents. He described his parents divorcing when he was seven years old. He stated that they both remained very active in his life and provided him with love, care and comfort. He described being unsure why his sister and brother are living with their addictions. He stated that his parents, even though they were divorced, were very supportive in his life. He suggested a reason his older siblings might have turned to drugs was being exposed to alcohol and drugs as children, when there were house parties occurring when they were asleep.

Onida is currently working towards a post-secondary degree in education. He indicated that he wants to make changes to the current school policies in regard to children who attend school and are HIV positive. He stated that his niece experienced tremendous stigma when his family was looking for a school for her to attend for

kindergarten. He stated that there were schools in the city that would not even accept her as a student because she was HIV positive. He described this as being unfair, as his niece was born with the illness; why should she be treated differently than other children. He described protecting her from the stigma and discrimination and stated that they have found a program that has accepted her and she is currently enjoying school.

#### 6.1.16. Paco (Gold Eagle)

*“I was told by a caregiver, that if I continued doing what I was doing that there was this new illness that I could expose myself to quite easily. And it scared me; it scared me into changing, somewhat. And it also, helped me to see what was going on, through a different lens.”*

Paco is a forty-six year old, Métis woman from Paul First Nation who has been affected by HIV for over twenty-six years. She reported having numerous Aboriginal friends who are living HIV positive. She stated that she became an advocate for HIV/AIDs within the Aboriginal community because of her personal experiences in 1985. At that time, Paco described living a risky lifestyle and because of the risk, she became aware of the new illness that was starting to affect Aboriginal community members. She indicated that she was concerned about the potential health risk that she and others in her community could be exposed to, by relations with those who were living high risk lifestyles, such as partying, addictions, unsafe sex, etc. She described that people at the time were not being informed about sexual health and that increasing the risk for the transmission of STDs and HIV/AIDS. She reported that her western prairie province did provide an anonymous clinic for testing. However, she reported that there



were no resources other than the testing (e.g. supports, programs or services) to follow the diagnosis.

Paco indicated that she is a single mother of five children and has dedicated her life to ensuring that her children's generation is equipped with the information that they need to make informed choices for their lives. She indicated that her children have attended workshops with her about HIV/AIDS. She described how her children are educated and how they understand her commitment to educating about this illness. She described some of her family members not understanding why she would work in this area if she were not living with HIV. She remarked that her immediate family supports her choices and that this is what matters most. She sought the guidance of the old people in her Aboriginal community and they embraced her, encouraged her and told her to share her experiences with others, giving her the courage and strength to continue on with this important work.

Paco described that the Aboriginal AIDS movement is in a transition time, where the process of being identified as HIV positive includes being a part of an in-group, where only HIV positive individuals can access supports. She stated that conversations are beginning where it is accepted that those living with HIV/AIDS have specific needs that are distinct and unique. Although, there are those like herself that are within the Aboriginal HIV/AIDS community that do not have HIV and are significantly dedicated to advocating. She reported that at conferences and workshops there are exclusive rooms that are set up for those APHAs to access. However, she remarked that if this is the case and someone is not ready to disclose and does not feel like they should walk through that

door, how is that inclusive? She stated that she would continue to pose these questions in the movement and looks forward to what the future holds.

#### 6.1.17. Satinika (Magic Dancer)

*“Because I think about my HIV sometimes and I think, wow, I feel guilty because I have not been sick at all, and my partner has almost died three times and he’s like only thirty nine. You know, there’s like a whole spectrum in there, of guilt, of dirty, there’s shame!”*

Satinika is 49 years old, First Nations Status two-spirited man from Cross Lake First Nation who has been living with HIV for over twenty-five years. He stated that he learned his positive diagnosis in his early twenties, while living in the United States. He indicated that when he was diagnosed, he was living a high-risk lifestyle that included addictions, prostitution and homelessness. He reported that when he first learned about his diagnosis he was filled with shame and disgust. He stated that he set out to drown his shame with addictions and became submerged for years in drugs and alcohol. He reported that after years of living an unhealthy lifestyle, his overall health was being destroyed by the addictions and he realized that if he did not stop, he would die.

Satinika described moving back to Canada as being very beneficial to his HIV/AIDS diagnosis. He reported that in the States he experienced major discrimination and stigmatization. When he arrived back in Canada he realized that there were other Aboriginal men like him who are HIV positive and he was welcomed into the Aboriginal HIV/AIDS community. Satinika was adopted as an infant from Canada during the sixties scoop, where Aboriginal children were taken away from their mothers and families through the child welfare system and placed for adoption and he learned of this through the repatriation process. At this time, he was united with a biological sister, who was also

adopted away from their family. The results of being adopted linked with the feelings of being disconnected from his culture and his biological family. He reported that deep emotional wounds exist because of the turmoil he has experienced throughout his life. He reported that one of the benefits of researching his biological family's roots was locating his relatives, and most members have fully embraced him as a family member. He stated that after being reunited for over ten years, this reunion has assisted him to heal emotionally. Although, he stated he still has much to continue to work on.

Over time, Satinkia reported that he has come to terms with being HIV positive because of the significant supports he has received from the Aboriginal HIV/AIDS networks he is involved in. He stated that he has been active in providing education and sharing his life experiences of living APHA for the past ten years. He currently speaks to First Nation communities about his life experiences and is an advocate for APHAs. He stated that it is important to promote harm reduction in regards to HIV/AIDS as this will assist in arming the Aboriginal communities with the information that they need to fight the virus.

#### 6.1.18. Takoda (Friend of All)

*“There is a few people that have it, and they just don't wanna talk about it. They hide it. I think that they should be more open. People talking with other people that have it. We should have HIV groups to talk and confidentiality for people to come out and talk about it.”*

Takoda is forty-four years old, First Nations Status woman from Muskoday First Nation who has been living with HIV for over seven years. She indicated that when she was diagnosed, she was living a high-risk lifestyle that included addictions, prostitution,

incarceration and homelessness. She gave birth to six children and her mother raised them for most of their lives. She and her common law partner recently started to raise the youngest of her children. She stated that in the past she was not capable of providing her children with the supports that they required. She was living on the streets for over thirty years. She described that being clean and sober for the past three years has really assisted her to come to terms with traumas, loss and the emotional traumas that she experienced in the past. She indicated that coming to terms with her past and living APHA has assisted her to make a decision to live a healthier life. She stated that it is also important for her to work towards becoming a mother to her children and a Kookum to her grandchildren.

Takoda described leaving home at a very young age and stated that she lived on the streets for the majority of her life. She reported that growing up with multiple addictions was a way of life and she thought leaving home would be a better choice. She reported that when she was a child, she had been sexually, physically and emotionally abused. She stated that her decision to leave home led her to the wrong path that resulted in more abuses in her life. She indicated that she shares her life experiences with youth on her reserve and at Aboriginal gatherings in order to prevent other Aboriginal youth to make a similar decision to leave home. She stated that it is time for the coming generations to have a chance to make better choices and reduce the rates of HIV/AIDS within the Aboriginal communities. She reported that it is her hope that if she can reach one person with her story, her story has assisted in empowering a person with knowledge about HIV/AIDS and she considers this a success.

Takoda is invested in working towards having more supports provided on reserve. She reported that in the past three years, she has been working with ASO's to build

stronger resources, services and supports for Aboriginal people on reserve. She stated that when a person has HIV on reserve, they face more challenges than an Aboriginal person in a large city. She described living on reserve and requiring a ride to attend medical appointments. She stated that she does not have a lot of choice when it comes to the services and supports that are offered on reserve. For example, when she is required to attend her regular monthly appointment with infectious diseases, she requires transportation that is provided with the health centre on reserve. However, for her to receive a ride, she has to disclose her illness/reason why she requires transportation. She has disclosed her status to her community, so this is no longer a barrier for her to face. Although, in other cases, not all people who are HIV positive choose to disclose their status's to obtain the on reserve supports (i.e. transportation). She described this as a barrier for those on reserve when accessing medial supports. She indicated that the way current medical services and policies are on reserve now, one has little choice but to disclose in order to receive the supports. In the past, Aboriginal people who have disclosed their HIV positive status on reserve have been shunned and driven away from their home reserve. She believes people act this way because people are not ready to deal with the illness due to the lack of education about HIV. She stated that currently she has support on her reserve and is quite thankful for the health care workers who provide this service and support. Although, she stated it is time for all reserves to accept this as an illness that our Aboriginal communities are facing and to stop the stigmatization and discrimination on reserve by educating.

6.1.19. Wapekai (Skillful)

*“My family wants to keep it hush, hush. It’s a non-discussable, not talking scenario and that’s the way they want to keep it. I want people to know that there is hope.*

*Unconditional love does exist. Just because you are HIV, doesn’t mean that you are dead. Even though they are HIV. Life has just begun because I am HIV.”*

Wapekai is a thirty-eight years old, First Nations status man from Whitecap Dakota First Nation who has been living with HIV for over nine years. He indicated that when he was diagnosed, he knew he had to keep it a secret. He described knowing other Aboriginal men who are HIV positive and he reportedly witnessing how they were treated badly and faced discrimination. He stated that he experiences multiple levels of discrimination. An example he shared was in regards to employment, as he had a hard time going to work when he was ill and often this resulted in the loss of his job at the time. He stated that difficulty maintaining employment was directly related to his HIV positive status because he required many consecutive sick days. He described that once he was able to manage the physical discomfort and cope with the illness better, he became psychically stronger, able to make it through an eight-hour shift and remain employed.

Wapekai was born to parents who were struggling with addictions and he reported that he was placed in foster care until the age of five. A non-Aboriginal family then adopted him, where he was exposed to sexual, emotional and physical abuses. He stated that as a child, he often felt that he deserved to suffer. The results of these childhood traumas were multiple years of addictions and living a high-risk lifestyle. As he matured, Wapekai realized that he did have a choice in the direction his life was taking. He sought out services and supports for a better life and indicated that he is now living the life he

had always wanted. He stated that growing up through the foster care system was not going to continue on as a cycle. He stated that it was time to break the cycle and choosing a healthier lifestyle without addictions has changed the momentum of his life, in a good way for himself, his partner and his children.

Wapekai described having a supportive common-law wife who provided him with unconditional support and love. They have been together for the past five years. He reported that he had wanted to have a child with his common law partner for a few years. He has three grown daughters, which he did not have a parenting role with. He described that he often thought that he would make a good father. He stated that after much debate in his head, he approached his wife to discuss the potential of having a child with her. She had a child already that they raise together. She agreed to have a child with him, even though he was HIV positive and she would be at risk for the infection while they worked on getting pregnant. He indicated that having his wife be willing to expose herself to the virus, to accept him for who he was and to provide him with a chance to be a parent was the most love he had ever felt in his life. Their daughter was born healthy and his wife has not tested positive for HIV.

#### 6.1.20. Yotin (Wind)

*“I knew they were talking about my brother, but I really did not want to believe it. I was angry, hurt and scared because I knew if I believed it, that it would become real. He has AIDS.”*

Yotin is a thirty-five years old, First Nations Status woman from Beardy Okemasis First Nation who has been affected by HIV for over ten years. She described learning about her brother’s diagnosis through gossip in the community. She reported that

when the rumors started, she wanted to ask her brother about it, but was afraid. She indicated that they had been raised by their Kokum and developed strong values as she taught them about their traditions. She described growing up on the reserve as the best life. They attended many cultural gatherings and developed a strong connection to their spirituality. She stated that she did not know why her brother had moved to the city and chosen a life of addictions. He has not returned to their community for many years and she stated that he would likely not come back alive. She reported that in the past year, she has noticed that he is looking unhealthier and suggested that it is likely due to his life on the streets and not accessing the medical supports that his body needs.

Yotin reported that they did not talk about sexuality, as this was a subject that was not to be discussed. She wondered if this had been discussed, would her brother be HIV positive. She built up the courage to ask her brother if he was HIV positive and he disclosed to her. He described living a risky lifestyle, having unprotected sex with multiple sexual partners, mixed with drugs and alcohol was a sure way to be exposed to the HIV virus. Her brother is heterosexual and the misconceptions that her reserve has about her brothers APHA status is that he is gay. She reported that he has told her that he is not gay and that all Aboriginal people need to understand that this virus is not a gay man's disease any longer. She stated that she feels it is time for First Nations communities to educate about safe sex in order to empower the upcoming generations about sexuality. Sex is a fact of life and should not be a secret.

Yotin reported that she had never spoken about being affected by HIV. She stated that she felt if people knew that she was talking about his illness, she would be exposed to the impacts of stigma and discrimination in her community. She stated that one of the



reasons why she volunteered for this study was to assist her to become more comfortable about talking about her brothers illness. Her immediate family has not discussed his brothers HIV positive status and it remains a secret that they have. She stated that it is not healthy for her family and the younger generations to live a lie. She stated that her children are becoming sexually active and she wants to educate her children about safe sex and protecting themselves from potential risk. She shared that if she and her brother had some discussions and education about how to protect them, maybe he would not have the virus. If she can prevent one of her family members from becoming infected with HIV, she has started a change in her Aboriginal community. She stated that it is her role to share information about HIV/AIDs, safe sex and safe drug use. It is time for things that have been kept secret to be talked about.

## 7. RESULTS

It is important at this stage to restate my interest in this topic. My interest in researching HIV/AIDS and Aboriginal communities emerged from my personal experience. I am a First Nations woman and I had a sister who was HIV positive. I was affected by HIV/AIDS since the time of her diagnosis over 25 years ago. I am also a researcher who has dedicated the past 12 years to qualitatively researching this topic with Aboriginal peoples in Canada, am training to become a PhD clinical psychologist and will work with Aboriginal communities. I have invested much time, effort and passion in this work over the past years and this research is very close to my heart. This dissertation provided a platform for Aboriginal Canadian participants to have a voice – an outlet to talk about their life experiences with HIV/AIDS.

Grounded theory methodology allowed me to discover a process of growth and transformation as well as other temporal dimensions of participants' experiences. Two theoretical models of Aboriginal community members' HIV/AIDS life experiences were generated based on the qualitative analysis (see Figure 1 and 2). Both APHAs and the APAAAs can be described as *A Journey to Psychological and Cultural Healing: Transformation of Identity*. Overall, the journey of healing that Aboriginal who are diagnosed with HIV/AIDS experience begins with access to services that are culturally relevant and supports that assist them in discovering who they are as Aboriginal individuals. They are then able to adapt and adjust to their diagnoses. In addition, their identities as Aboriginal individuals become particularly salient and important as they claim their identities as APHAs. Their journeys are depicted as flowering trees (see Figure 1). Seven themes were abstracted from the original interview data for APHAs:

*Acceptance of Identity, Psychological Strength, Family and Relationships, Historical Trauma, Formal and Informal Supports, Services and Culture as Healing.* The seven themes are made up of subthemes (See Table 2). Four themes were abstracted from the original interviews data for the APAAs: *Psychological Experiences, Historical Trauma, Family and Relationships* and *Culture as Healing*. The four themes are made up of subthemes (See Table 3).

Table 2. APHAs: Seven Themes

Propositional Theory	Themes	Subthemes
<p style="text-align: center;">A Journey to Psychological and Cultural Healing: Transformation of Identity</p>	<p style="text-align: center;">Historical Traumas</p>	Colonization
		Sexism
		Racism
	<p style="text-align: center;">Family And Relationships</p>	Foster care/Adoption
		Biological
		Friendships/Surrogate families
	<p style="text-align: center;">Psychological Strength</p>	Self Esteem
		Stigma/Discrimination
		Confidence/Courage
		Resiliency
	<p style="text-align: center;">Services</p>	Accessibility
		Limitations
		Service Provider
	<p style="text-align: center;">Supports</p>	Peer-to-Peer
		APHA Support Groups
Counseling Services		
Education		
Engaging Community Members		

	Culture As Healing	Validating Traditions ----- Cultural Gatherings ----- Elders ----- Culturally Safe Counselors
	Acceptance of Identity	Denial and Loss ----- Shame ----- Acceptance of Diagnosis ----- Advocate

7.1.1. Theme: *Historical Traumas*: The first theme that emerged from the APHA interviews described *Historical Traumas* as being responsible for some of their life circumstances. Throughout the interviews the APHAs described historical traumas that they had experienced throughout their lives that have had direct emotional impact on their *Journey of Transformation*. Ultimately in the grounded theory analysis, the subthemes of *colonization, sexism and racism* emerged within the theme of historical traumas.

7.1.1.1. Subtheme: *Colonization*: First the subtheme of colonization was identified within the theme *Historical Traumas*. The concept of colonization was described by APHAs in terms of feeling not accepted by their community and surrounding communities because they were Aboriginal. This contributed to further emotional trauma described by the participants in relationship to the results of colonization. For example, Donoma recalled:

My first experience with the education system. There was a white end and an Indian end. You know. We lived in the Indian end, so we were obviously Indian. The white end of town had everything, where everything was. They had the school. We didn't have anything for education on the reserve and if we were lucky, we got to attend the school there in the white end.

Some participants described that they have utilized traditional medicines for HIV/AIDS.

However, they do not trust the non-Aboriginal medical systems with traditional medicines because of the historical mistrust that has occurred in the past. Elsu stated:

“One thing [traditional medicines] that we can't share with the pharmacists, we are scared that they will take that away and do their own thing, like they have all through history.”

He described experiencing current challenges with health care and the government, which has impacts on the health of himself and ultimately on Aboriginal people. For example,

Elsu stated: “The federal and provincial governments treat us with stigma and discrimination with our health care systems because we are Aboriginal. They don’t understand us. They keep cutting back on our health care coverage and needs.” Esarosa described a time in his life where he felt that the results of colonization had affected him personally in his understanding of his heritage. For example, when he first learned about his Aboriginal heritage, it was a confusing time, as he had not been raised with knowing he was Aboriginal as a child and only became aware of it when he was an adult. He stated:

I went back to school and I found out about what it was like, being Aboriginal. We had to do a research paper about who we are, as a people. That’s when I started talking to the grannies, aunties and uncles. I found out I was Blackfoot. Then everything came out that my family had hidden away because it is shameful to be an Indian.

Huyana described an experience where he felt that the professionals who were providing support were exploiting the Aboriginal people accessing services, which he stated directly, related to the results of colonization. He stated:

I’d say the biggest fear is the racism I face on a daily basis. It comes from those who have professionalized helping people who live with HIV and AIDS. If you are not mentoring, normalizing and creating opportunities for them to break the cycle of poverty, then all you are doing is exploiting them.

Jacy stated that the results of colonization on her people have lasted for generations. She believes that children today do not have the tools they need in regards to emotional development and connection. She stated: “They [youth] don’t have respect because we have an entire generation of youth out there with a distorted thought process of love. They don’t know love. To them love is beatings, pain, abandonment, loneliness. This is [HIV/AIDS] here because of the government and the churches, they changed us.”

7.1.1.2. Subtheme: *Sexism*: The second subtheme of sexism was identified within the theme *Historical Traumas*. Interview participants described personal experiences that they had endured as women in regards to sexism. Huyana described experiencing historical traumas and challenges in regards to her identity and the results of residential schools and the sexist Indian Act. For example, she stated:

In residential schools, they taught us [Aboriginal people] to be greedy, to hate, to be abusive, sexual abusive, all of that. In our culture, that didn't exist before. If someone did do something in the community, they would be banished. Men treat women with no respect now. Women are the givers of life. Residential schools changed this for us!

Takoda described experiencing discrimination because of her sex from an early age within her family and she recalled it stemming from a historical perspective. She stated: "I knew that I was never good enough, as my brothers were. The boys could hunt, they could fish and all I was good for was making babies. That's why I left; I went to the streets because my family had it all mixed up because of residential schools. Women used to be respected, now we are baby makers or punching bags."

7.1.1.3. Subtheme: *Racism*: The third subtheme of racism was identified within the theme *Historical Traumas*. Donoma described feelings of discriminations she experienced as an Aboriginal woman and also being APHA. She stated:

So, there was always this underlying racial tension, everywhere we went. I think having that experience as an Aboriginal person, as an Aboriginal woman, prepared me in many ways for the stigma that I would know I would face as a person living in poverty, a woman with HIV. Having those experiences early on with racism and stigma made me very mistrustful.

Elsu described being brought up in BC and recalled as a child experiencing racism that resulted in eventually building emotional strengths for him to deal with racism throughout his life. He stated: "I grew up in rural ... which at the time was very



European. Very white. The white world. I mean I look at my class pictures and there was nobody else like me [brown skin]. So I dealt with racism and discrimination as a child, in my early years. So now if someone says something to me, I just tell them, I inform them!”

7.1.2. Theme: *Family and Relationships*: Throughout the interviews APHAs described either a connection or disconnection with family, extended family and surrogate families as they related to their experiences of being HIV positive. Some participants described how their childhood family experiences assisted them in developing emotional and spiritual well-being along their *journeys of transformation*. For others, family and relationships were not always caring ultimately affecting them emotionally throughout their lifetime. Through the analysis the second theme of family and relationships seemed to be comprised of three subthemes: *foster care/adoption*, *biological* and *friendships/surrogate families*.

7.1.2.1. Subtheme: *Foster Care/Adoption*: First the subtheme of foster care and adoption was identified within the theme of family and relationships. The concept of family described by APHAs emerged as consisting of non-traditional family forms, where numerous participants were raised within the social services/foster care system or were adopted. Feelings of abandonment and disconnection from their biological family and roots had lifelong effects. Some participants expressed in the interviews that these challenges and experiences assisted them to develop extended family relationships and surrogate families. Elsu stated: “I don’t have any real family. I don’t have any blood relatives because of the foster care system. When I met my [biological] cousin and sister, we just didn’t connect and I just left it there. So I didn’t search for my father or my

mother, or brothers or sisters.” Wapeka stated: “I was in and out of foster care when I was a kid. I never felt like I had a family. My common-law partner is my family. I didn’t know how to love! She teaches me how to love and I’m old!” Huyana stated: “I was 12 years old experiencing the foster care system and experiencing different cycles of abuse, in the family. It all traced back to the residential schools. My siblings weren’t there. My dad wasn’t there. He like totally retreated!” Takoda stated: “I left home at 11 and went to the streets. I was in and out of foster care. I had nowhere to go, so why not live the street life. I was on the streets for over thirty years of my life.”

Some participants described having good relationships with their adopted families that assisted them in developing their emotional well-being throughout their childhood and into adulthood. Strong relationships within their adopted families emerged as a strength in regards to their lives as a whole. For example, Citali stated:

I was adopted at two and a half. I recently started searching for my biological family. Just the way I was raised by white people, I was very loved! My father, although he worked at... penitentiary, so you can imagine how much stress and stuff . It was difficult. I was the youngest of four, all adopted from different families. I was raised to express myself, my feelings and stuff like that!

Satinika described being raised within a loving adopted family, which he knows was a blessing, as he was a product of the sixties scoop. He stated: “I was adopted away from my First Nations community and raised out of the country. I was supported by my adopted family with love and respect when I decided to return to Canada to find my biological family. They are behind me 100%.”

7.1.2.2. Subtheme: *Biological*: The second subtheme of *biological* family was identified within the theme *family and relationships*. Although a large proportion of the APHAs had been raised within the foster/adopted families, those who were raised within

their biological families described the importance of them being a part of their lives. Some participants expressed feeling supported unconditionally by their biological families. They described feeling love and respect from their families was important in developing feelings of self-worth along *Journey of Transformation* as APHAs. Jacy stated: “My mom! I have my mom. She supports me no matter what! My kids, they support me too!” Lakota described his mother’s support as being the light at the end of a very dark tunnel. He described feelings of being worthless and felt loss when he was first diagnosed. His shame prevented him from telling his family, until he felt he was close to death. Lakota stated: “I knocked on her [mom] door, and I said Ma, I came home to die. I have HIV and Hepatitis C. She gets me. My mom, she’s tremendous! Actually, my mother, she is my biggest supporter.” Makya described his mother being credited with providing love and support. He stated: “I was ready and when I got tested, I went and talked with my mom and I told her I got tested for HIV. And my mom, I cried to her, and she supported me, loved me. But finally she told me to go and get help for my depression. And so I did. She is my reason for living a better life!”

APHA participants described emotional experiences in their biological families ranging from unconditional love to complete loss. Often times they expressed feelings related to their immediate families that ranged on the spectrum of acceptance and being supportive, to the extreme range of total abandonment. Lakota recalled: “My brother is a supporter of me to some degree. My sister, she’s pretty shy about it [HIV diagnosis].” Satinika described “I was afraid to tell them, I knew that they would disown me if I did. My uncle was HIV positive and he was disowned. I knew if they knew I would be dead

to them.” Esarosa described the feelings of loss and abandonment that he experienced from his father. He stated:

My dad, when I went to visit, he went in the other room. If my mom invited me for dinner, all of my stuff had to, um, I couldn't sit with my family. It was almost like being treated like a dog. But the dog was treated better. I couldn't sit at the table. Everything I used had to be bleached, because they didn't know nothing about it [HIV].

Wapekeda stated: “My family wanted to keep it [HIV] secret, even though some of them are also living with HIV or Hep C. This topic is not up for discussion in my family; it's so shameful. I always feel like out of place and I don't belong in my family.”

Donoma described how her strengths emerged from the love of her family, who love her unconditionally. She recalled:

I eventually moved back here (the reserve) to have the family support. You know, that was hard at first. I was angry, hurting, I was depressed, there wasn't a lot of experience with this in our family. So it really was a learning experience for everybody, a journey, really. But there wasn't any fear, of me.

APHA participants described being mothers and fathers to children, as well as experiencing pregnancies while APHA. Participants indicated that it was important for them to have their children understand that they are not alone in the world and other children also have parents of loved ones who are APHAs. Donoma stated: “I wanted my children to know that it [HIV] wasn't any different than diabetes or a sickness that could be managed. I knew that if they were there for me, I could do anything. I raised them with that fact that I was HIV positive and they love me unconditionally!” Esarosa described being a step-parent as he and his partner co-parented his partner's sons. He recalled: “The boys were like 3 and 4. They knew we were HIV positive from a young

age. They accept us and that's all that matters. Our kids have grown into strong young men!"

7.1.2.3. Subtheme: *Friendships/Surrogate*: The third subtheme that emerged from the theme *family and relationships* was *friendships/surrogate families*. APHAs described feelings in the interviews that related to the abandonment and loss of family. Some participants described feelings of disconnection from biological families that ultimately affected their feelings of self-worth. Participants described creating their own family relationships, surrounding themselves with good strength and energy. Interview participants described how with the creation of surrogate families there emerged strength, self-worth, strong connections and relationships. For example, Guitan stated: "I had very little contact with my family of origin. I got all of my support from my extended family. You know the family that gay people need to make and survive on until their family of origin gets their shit together!" Awan stated: "Because my family is not close by, I don't live there because of the hate crimes; they hate gay people. My cousins taunt me, my extended family have disowned me. That's why I am here in ... because being gay is accepted. So that's my family now, here in.... Living here is safe and I have my community, that's my family now!"

7.1.3. Theme: *Psychological Strength*: Throughout the interviews APHAs described initial feelings that affected their psychological well-being that ranged from mixed emotions and feelings such as grieving a loss of themselves, feelings of depression and ultimately building themselves back up psychologically, emerging as resilient individuals. Further analysis of the data revealed four subthemes that illustrated the *Journey of Transformation* that participants experience in regards to their psychological

strength of living HIV positive. The four subcategories that emerged from the interviews are made up of *self-esteem*, *stigma/discrimination*, *confidence and resiliency*.

7.1.3.1. Subtheme: *Self Esteem*: Changes in self-esteem accompanied the HIV positive diagnosis with most of the APHA participants. The diagnosis of HIV resulted in a myriad of emotions. Most participants shared feelings of being at their worst (i.e. ‘rock bottom’), which ultimately changed with gradual acceptance of their HIV diagnosis. Specifically, self-esteem issues emerged once diagnosed, often related to their early childhood and adolescent developmental years, that triggering unresolved emotional issues. Citali stated: “I was empty. I was lost. I felt like I didn’t belong, just felt an emptiness. It’s weird, it feels like your soul leaves your body. There is no feeling, like you don’t have real feelings.” Makya shared feelings of low self-esteem that emerged from his HIV diagnosis and ultimately how he felt in the moment. He stated: “You know the fear; of who’s going to want me. And, I am going to die. What’s the use of living? That’s why I kept to myself because I did not know how to talk about my feelings.” Makya stated feelings of low self-esteem as a child and how it has had generational impacts within his family. “From my past of going through sexual and physical abuse. Learning very early that, you don’t talk, you don’t trust, you don’t feel.” Jacy described little regard to her physical well-being, as she also experienced feelings of low self worth when she was struggling with addictions and using. Jacy stated: “I didn’t care! I didn’t care what I was using and if someone else had used it [syringe].” Huyana described feelings of loss of her childhood and low self-esteem. Huyana stated: “It goes back to residential schools, we were treated like animals. The government used us to try to make us something we are not... It goes way back to my grandparents being in residential

schools. Cycles of abuse; trust issues. I don't even know how to have relationships! I didn't know how to trust!"

Some APHA participants indicated that they believed that the HIV diagnosis assisted them in building a sense of self worth and emerged as feelings of self-esteem that they had not experienced prior. When Esarosa was diagnosed, he was living a life with little self-worth and stated he was in a relationship with a married man, while he was also married. "It was a mess, because he has kids, both of us were married. I started to tell some of my friends [about HIV diagnosis], and I lost a lot of them." Following the loss of friends, he found he still had a lot to live for and credited this to his strength to rebuild his self-esteem. For example, he stated: "I live a balanced life now. I don't have stress in my life because I live a balanced life since becoming [HIV] positive." This may have been influenced by his connection to medicine wheel and the balance that he described emerge from his connection to the medicine wheel teachings. Another participant indicated that his feelings of self changed from being negative to a stronger sense of self that guided him, once he knew he was HIV positive. Guitan stated: "Finding out I was HIV positive. It opened up, my whole world, it started me to find the red road."

7.1.3.2. Subtheme: *Stigma/discrimination*: All participants described difficult feelings and emotions that accompanied the HIV diagnosis. They shared life experiences of being in situations where they had experienced stigma numerous times that often accompanied discrimination. For example, Citali stated: "Living in an urban setting is more helpful, yes. Because the people, their attitude towards diseases like AIDS, they are a lot more accepting. On the reserve, its [AIDS] not accepted on the reserve." Donoma described when she was still using and was living on the streets, the drug addicts had a

name that they would label the HIV positive women with. She stated: “I experienced violence, abuse and rape. And the thought of someone harming me because I was ‘taboo’, that’s what they used to call it right. They wouldn’t even say AIDS. So if someone was taboo, you wouldn’t touch any of their needles and things.” When she returned home and started advocating for HIV and educating in First Nations communities, she recalled experiencing further stigma and discrimination. Donoma stated: “I had parents that wouldn’t let their kids sit in the same room as me because I have AIDS. They were afraid of their kids breathing the same air as me!”

7.1.3.3. Subtheme: *Confidence/Courage*: The concept of feelings of confidence and courage accompanied the HIV positive diagnosis with most of the APHA participants. These feelings eventually emerged to assist in strengthening their psychological well-being, with courage and building confidence in acceptance of their diagnosis of HIV. Most participants shared experiencing feelings of fear, anger, rage, doubt, loss and grief that ultimately resulted in facing the diagnosis with strength, courage and confidence. Following their disclosure of the illness to their partners, family, friends, etc., most participants described strength and confidence once they had disclosed their status on their own terms. Although, some participants confided in people who ultimately broke their trust and disclosed the diagnosis without permission when APHAs were not ready to share. The experiences of broken trust eventually emerged as confidence, once they had embraced their HIV positive diagnosis. For example, Awan stated: “I confided in my cousin and she told everybody. I was hurt! I thought that I would have told everyone individually. I was the one going through it and it wasn’t for



her to tell everybody for me!” Elsu described his band office as being a stigmatized environment for a HIV positive person. He stated:

The band councils, they worry about how HIV/AIDS will affect the communities. I mean, how do you tell people in a small community of maybe 100 that you are HIV positive? How do you go to your band council and say ‘I need to travel because of medical needs?’ They will ask, what are your medical needs? And whether or not you are ready, you have to disclose to them to receive care.

Esarosa described friendships that he had had for most of his life ending because of his HIV diagnosis. He stated: “It was almost like I had the black plague! I’d call. They wouldn’t call me back. They wouldn’t pick up my calls. I would write them letters. They wouldn’t write back. It was then that I really started feeling isolated. When I was growing up, they were my best friends.” Eventually, he developed new relationships and friends that supported him unconditionally.

7.1.3.4. Subtheme: *Resiliency*: The concept of feelings of resiliency accompanied the HIV positive diagnosis with most of the APHA participants. Participants described that being gay, HIV positive and Aboriginal comes with numerous challenges, which at times, may result in being rewarding in significant ways. Guitan stated: “In Aboriginal culture, gay people were actually a part of the whole. I started to find a place where I belonged. And this new place that I belonged, talked to my heart.” Resiliency resulted from life experiences of APHAs that have had experiences of intimate partner violence, emotional abuse, sexual abuse, street life, addictions and tragic events. Huyana stated: “I’ve been an urban Indian all of my life and throughout my lifetime, I’ve been subjected to the child welfare system, violence, abuse, drug and alcohol abuse, gangs. My mother was murdered when I was 12. I learned to live without her. I learned to survive.” Makya stated:

My problems seemed insurmountable, that I couldn't deal with them. I wanted to stop drinking and I wanted to be happy. I didn't know how to stop drinking and I didn't know how to be happy. And I started thinking about all of my issues, residential schools, sexual abuse and all of that shit! Then I just started drinking.

Another participant described difficult feelings that emerged in her experience that assisted her on the journey to transformation. Her resiliency was related to battling mental health issues. Jacy stated: "I went through a lot of depression and started using drugs and alcohol, for four years straight. I knew I had to start taking care of myself. I've been clean for awhile and take meds for my depression." Huyana described having a challenging life growing up that she stated she would not change one thing. Strength emerged from her life experiences. She recalled:

Do I regret? No, I can't! I have to be grateful and thankful. Because you know what? I am. With all the bad came good too. It did happen for a reason. You know like, when I was young and I didn't have my bros teaching me how to hustle. I could have been selling myself on that street corner and ended up in a ditch somewhere. Dead or missing! Do I regret? It could have been worse. That's what my life is, it was worth it!

7.1.4. Theme: *Supports*: The fourth theme that emerged from the APHA interviews describes *supports* as essential in the process of living HIV positive. The interview participants indicated that for them to be healthy and to be able to take care of their needs, *formal and informal supports* are required. Subthemes emerged from the participants interviews that described having *peer-to-peer supports, APHA support groups, counseling services, education and engaging community members* within the Aboriginal community as beneficial for helping them in their journey of living APHA.

7.1.4.1. Subtheme: *Peer-to-peer supports*: The first subtheme of *peer-to-peer supports* was identified within the theme *Supports*. APHA interview participants shared experiences that depicted supports that they felt were essential for helping them in their

journey of living APHA. Donoma stated that peer support was beneficial, especially when she was expecting her first baby and she was APHA. She described a program that was offered at the time that has since been closed. She described the support that had been provided for herself and other APHA mothers as building a community of peer-to-peer support. Donoma recalled:

Peer counseling. One thing I really miss is having a peer-networking clinic. When I was first pregnant with my daughter, I went to...clinic for women and children. They were seeing all of the women, pretty much...When I got pregnant, at first I thought I was the only one, the only positive woman in the whole world having a baby. And, when I got hooked up with them. They said 'well we do a luncheon.' For positive moms and what they did is they coordinated all of our Dr.'s appointments at the same time, so we would come and have a lunch together while we were waiting for our appointments. They don't do that anymore. And I thought they are really missing the mark here. Why didn't they set up ASOs in the hospitals? That's where our women are!

Guitan described that an important support is having a peer support/mentor there when the HIV diagnosis is first communicated by the health professions; this support person would assist in creating a strengths-based support with Aboriginal community members within the first hours of the diagnosis being given. As well, he indicated that there needs to be APHAs involved in all aspects of support. He stated:

I'd like there to be a HIV positive person in the room with the health professional when the diagnosis is delivered. I'd like there to be a HIV positive person, the first person that they meet when they walk into the agency, of the local AIDS Service Organization. I'd like to see a positive person being the executive director of the said AIDS service organization.

Awan described the time when he first learned his positive diagnosis; he was called into the clinic by his doctor and instructed to bring a support person with him. He stated:

I was diagnosed in 2005, and it came as a shock to me. I didn't know where, know who or what...My best friend came with me. It was at an Aboriginal place. It was the place I was tested at and they have a lot of healing circles and stuff.

They have spiritual healing. All kinds of native traditional and culture, medicines and stuff like that.

Donoma described the importance of APHAs educating Aboriginal people as peer-to-peer mentors and as formal supports. She stated that it was important for her to share her story, as it seemed that there was a strong connection when she shared her story within Aboriginal communities. Donoma believes that supports such as peer-to-peer supports are effective in sharing information and ultimately will assist other Aboriginal community members in gaining information and hopefully help people make more informed choices in regards to preventing HIV. She stated:

So I would go and talk to their youth and you know, whoever would listen and you know the tools, the approach of education that we did at that point, which was going and telling your story and giving basic information. It was probably one of the most successful ways of education. Like every person that I talked to, you know, these older women, they would say, you remind me of my niece, you remind me of my granddaughter, you know, you could be my kid.

Hyuana believes that in order for trust to be created, there needs to be a level of common experiences that connect them. She described learning the most from others who are diagnosed with HIV. She recalled: “Because they are the ones living it. You know, and I would rather sit down with my peers and talk with them and educate them, more than somebody of authority. Because in the past, I have gotten scolded, or basically told what to do.”

7.1.4.2. Subtheme: *APHA support groups*: The second subtheme of *APHA Support Groups*, was identified within the theme *Supports*. APHA interview participants shared experiences that having other APHAs support them throughout their journey; it was essential in their *transformational journey* of living APHA.

Jacy indicated that she would like to see supports groups provided within her northern Aboriginal community for families who are affected by HIV. She described having the need for community events where information and education about HIV could be provided. Jacy stated: “There needs to be family involvement. There needs to be [places] where children can meet other children. Or there needs to be families getting together. People getting together. There needs to be a community event. You know even once a month, at a feast or something. It needs to be done. People would come.”

Esarosa described being invested as an APHA and mentor who provides informal supports for others who are APHA. He shared why he and his partner provide APHA retreats and informal supports as they navigate their healing journeys. Esarosa explained:

When I do healing circles, using the medicine wheel concepts of being in all four quadrants. Like, the four colors. Around anger, grief, fear, society, community, family, elders, so I try to incorporate that in my teachings... So my job, as helping people on their journey is to reclaim your own voice. It's what happened to our grandparents, residential schools, etc. And it's part of our history. Not who we are, it's only a part of history and that's the part that we need to embrace and keep.

Elsu described having an APHA support group weekly as a recommendation to improve supports in the western city that he currently resides in as being something he looks forward to. He stated:

I'd like to see our Aboriginal organizations in Vancouver have a cultural APHA support group, every two weeks or at least once a month. Because we don't have it. We don't have any elders, to come in and do the prayers and you know the smudges and make sure food is there.

Guitan described growth in supports and services since first being diagnosed. He stated one of the strengths in supports that he would like to see across Canada is APHAs providing them. He stated: “I want to see myself reflected back to me. At the agency I

attend for services, in the support groups...SO I am all about peer based. I think that any professional working in the AIDS field should be mentoring, encouraging PHAs and cultivating sustainability within the PHA community.”

7.1.4.3. Subtheme: *Counseling Services*: A third subtheme of *Counseling Services* was identified within the theme *Supports*. APHA interview participants shared how vital and important having counseling as a support is in their path to the *Journey of Transformation*. Most APHA participants described limitations in regards to available counseling. Although some APHAs described receiving counseling services and described this as vital and meaningful. For example, in Canada in 1980, HIV/AIDS counseling was limited. Esarosa indicated that when he was first diagnosed in the eighties, there were limited supports available to him in Canada, and he ventured to the United States to receive counseling and PHA supports:

So I talked to my ma. We both sat around and cried, because she was sick with diabetes. And we would talk about that and us and we'd talk about who was going to go first and what we want. Just to make it comfortable. I was going to find support and I couldn't find very good support where I lived at, in the...area. So I ended up having to go to the states. And that when I started my healing journey. And so, going over to the states and a very diverse group, a really mixed group. Mixed with Natives, blacks, whites and they gave me information. I got all of this information. That was the start of it.

Guitan described the need for counseling services as a support for APHAs. He stated that it is important that the provider know about HIV/AIDS and be knowledgeable, as he does not believe that support can occur unless there is experience. He stated:

The counselor has to have experience. Be up to date. Provide unconditional support. I have to trust them. Right off the bat, I had to find someone who was HIV positive to be my counselor. So I know he knows. There was a level of trust there that I would have never have had with any other previous health care provider.

Makya was working on emotional issues that had resulted from historical traumas. He described addressing these issues with a psychologist who was culturally safe and stressed how important that this was for his sessions. He recalled: “My psychologist had the understanding of my history as an Aboriginal person, well First Nations person. I was working with my psychologist, and I knew he knew my history. He was kick ass! Like to have that understanding of who ‘we’ are. It helped so much!

Iniabi described feelings of trust as the top priority for him to attend counseling services. He described experiences multiple traumas in his lifetime and wanted to be sure that when he attended counseling sessions that he would receive the supports. He recalled: “Trust is number one. Being professional, polite, courteous, informative and knowledgeable. They have to have the whole package. Also, non-judgmental. Confidentiality. So if all of those things are in there, then I will be willing to attend a session.”

7.1.4.4. Subtheme: *Education*: A fourth subtheme of *Education* was identified within the theme *Supports*. APHA interview participants shared how important education and awareness is in their *Journey of Transformation*. Most APHA participants described limitations in regards to education on reserve. Numerous urban APHAs described receiving education and resources through AASO/ASO’s. Although most agreed that there is still work to be done to create awareness, provide education and promote prevention.

Jacy recalled how she had sought out HIV/AIDS education for her children to learn about coping and living with a parent who is HIV positive. She was frustrated about not having education available on her reserve for her children to help her children to

understand more about the APHA illness. She indicated that a few years ago there was an opportunity to access a camp that was open for kids who are affected by HIV or are an APHA. However, she shared that her children did not feel accepted in the camp and left the camp early. She states she does not want to send them to another camp until it becomes more culturally safe. She stated:

They didn't fit in. And my kids were raised in the bush. Putting their hands in bear meat. They didn't fit in. It wasn't something that they enjoyed. Especially not for this northern community. Where we are all raised in the bush, right in the bush. Like literally. Moose meat's our main food and you know berry picking in the summer time, that's us. There is nothing available for us.

The participants suggested educational information should be provided about historical issues and Aboriginal communities. Interview participants suggested including information on the Indian Act, residential schools and the sixties scoop as a way to empower the Aboriginal communities to gain a better understanding about their culture, as many of the participants had not learned about historical issues as children. Makya described the process of putting together an educational package for workshops he created for APHAs. The importance of including historical issues that Aboriginal peoples in Canada have experienced, as he believes there are many connections between the historical issues and HIV. He stated:

I started doing the history of Aboriginal people, and the residential school system and the Indian Act and all of that. One of the APHAs said 'you should take this into the schools.' Because he didn't know about it right. And that's one of the things you have to do. Reclaim our identity as being Native. As a First Nation's person. You know, because of residential school, I didn't know what being Indian was all about!

Guitan described the importance of educating professionals who are pursuing degrees in helping positions, such as social workers and stressed the need for them to be educated



and also the importance of cultural sensitivity. Guian stated: “They want to be a social worker. They want to learn how to help people. They need to be aware of the treaties. The way the government forced us to attend school. They have to be educated about us!”

7.1.4.5. Subtheme: *Aboriginal Supports*: A fifth subtheme of *Aboriginal Supports* was identified within the theme *Supports*. APHA interview participants shared how important is in their *Journey of Transformation*. Esarosa described a preference for the front line service provider to be of Aboriginal descent when he was accessing services and supports. He stated: “I prefer the service provider to be Aboriginal, because I am black and native. And I find it hard not to see somebody that I can identify with. I need to feel safe.” Citali providers of supports and services should have cultural background and protocols when they provide services to APHAs. For example, he stated:

We don't have a lot of Aboriginal people who provide services in the ASO's. Here in ...Native Child and Family Services, Two-Spirited People, Anishanawbe Health, the workers are white. They don't have the background about us, my culture, my background. There needs to be more Aboriginal people working in these agencies.

Donoma indicated that she believes that the HIV/AIDS education and presentations that she was a part of were successful in the Aboriginal communities because she was Aboriginal. She stated the importance of hearing life experience from another Aboriginal person as being significant in creating awareness and support. She stated:

If I had gone in as an outsider. Like a gay white man or somebody else. I don't think they would have taken it seriously. I don't think they would have believed it. You know, somebody from their own Nation was coming and saying, I am a APHA. You need to be aware.

Elsu suggested the inclusion of front line health care workers being Aboriginal as important. “Why don't we have a social worker that is Aboriginal? We need this! Our

ways! Our culture! Some of us do sweet grass and when you are in the hospital, that's one of the best medicines to do.”

7.1.5. Theme: *Services*: A fifth subtheme that emerged from the APHA interviews indicated *services* as essential in the process of living HIV positive. In reading and re-reading the interviews, I identified subthemes within the overarching themes of *Services*, which included: *accessibility* and *limitations* for helping them in the journey of living APHA. Accessibility of services such as ASO's and AASO's (i.e., services) was a strength for some and for others a limitation. ASO/AASO services are most often located in larger cities across Canada. This was highly beneficial to those Aboriginal community members that could access them. However, on-reserve Aboriginal AIDS supports and services were almost non-existent. This resulted in a challenge in regards to seeking services and supports for those who live on reserve.

7.1.5.1. Subtheme: *Accessibility*: A subtheme of *Accessibility* was identified within the theme *Services*. APHA interview participants shared how services accompanied them in their *Journey of Transformation*. Services are described as being accessible for some participants. Conversely, participants described challenges that they encountered when attempting to access services. Elsu stated that when he first learned of his APHA diagnosis, it was devastating. He shared that having good services, such as education and up to date information from front line service providers made a huge difference after the first days of his diagnosis. Elsu explains:

So, she came in, thank god we had good supports there from the nurses. I was crying, he was crying, and he said, 'I'm not going to leave you', which was really good to hear. That was the first thought I was thinking, 'He's going to leave me because I am positive.' The nurse basically took him aside and said, let's go for tea and have a little talk. She was a well-educated nurse. She told him everything that he needed to know.

Iniabi described some of the challenges that he views as barriers when accessing services. An example he shared was the services he might have accessed were only provided to an individual if they qualify by disclosing they are a person living with AIDS. He indicated that he did not disclose his status to anyone, for more than two years. He described this was a barrier in regards to accessing services. He stated:

I'm becoming more aware and accepting to tell people now. This was a long process. I know there are organizations out there that can help. That are willing to help. I am not alone. But if you don't look, you are not going to find it. I really didn't want to look. I stayed out of it, the APHA community, the gay community, for 12 years. I wasn't aware of the PWA and ACT and other organizations. I didn't access those services for a long time.

Lakota indicated that from the onset, he has been accessing services since receiving his APHA diagnosis over 26 years ago. He stated that, at first it was a challenge to accept his diagnosis. However, over time, with services and supports he has come to terms with his illness and is currently an advocate in the APHAs community, which he stated has become more accessible over the years. Lakota stated: "I access CAAN and other ASOs in Alberta, Atlantic and Pacific provinces. I am involved in the supports and services."

Makya indicated that he had been on a long journey of recovering from addictions which he described resulting from experiencing multiple traumas as a child, including residential schools, foster care and addictions. He indicated that at the time he was diagnosed, there were limited services in the large city where he lived in western Canada. Although, he indicated that that was over twenty years ago and much has changed, he stated that at the time, he felt that they had one of the best addiction services offered, including mandatory counseling. He described an addiction center as providing him with

life changing counseling services that were accessible for him to start on his *Journey of Transformation*. Makya recalled:

So I walked through the doors of the ... detox centre. Even though I was on Ativan, I didn't know what was going on. I was scared shitless. And it was different, that ...detox, because it was mandatory to talk to a counselor, and they had a program, it was an hour-long program, everyday which you had to attend.

Jacy stated that there are addiction issues that have been affecting her community for generations. She stated that there are no supports or services for her northern Aboriginal community members to reach out for in regards to the addiction issues. Jacy recalled: "There is a lot of alcohol and a lot of drugs, you know. We had six kids die last year, here in this area from different things. Murders, beatings, hung themselves. Injection drugs, alcohol and drugs are there. They need something for kids. There is nothing, need something for the kids."

Huyana described that it was a challenge for her to access formal services for her newborn daughter when she left the hospital. She was aware of other provinces having a baby formula program. She had thought that her prairie province would also have this offered as a service for her to access when her newborn arrived. Unfortunately, not all provinces provide the same services to new APHA mothers and this limits accessibility for services:

Of course I mourned the fact of not having to be able to breastfeed. And that bonding, right. But I've made it through that. At first it was very difficult, in even trying to access any information about it or of what I was allowed through social services... Like they are not even educated that way, that I can't breastfeed. My social worker is supposed to be, to help people with disabilities, he doesn't even know, he's not even educated about HIV.

Iniabi described formal and informal supports that he was aware of for HIV/AIDS in his community. However, he stated that until he was ready to accept the illness himself, he was not open to accessing them. He shared how he preferred to work through challenges on his own, in his own time. Inabi stated:

Ok, there are organizations out there who can help and that are willing to help and I am not on my own. But if you don't look, you are not going to find it. You know, and I really didn't look because I stayed out of it, the APHA community, the gay community, for 12 years. So I didn't access those services for a long time. It was a very lonely process.

A few participants stated that they accessed formal services within their provinces, camps specifically for PHAs/APHAs/APAAs. The camps formal services and supports received both positive and negative reviews by the parents and children. All participants agreed that there is a need for more camps and support groups for their children to attend for support. Although, many APHA participants described that much is required to be adapted (e.g. cultural specific, culturally safe, Aboriginal support workers at the camp, etc.) before they would allow their children to attend another camp.

7.1.5.2. Subtheme: *Limitations*: A subtheme of *Limitations* was identified within the theme *Services*. APHA interview participants shared how services were limited in numerous aspects. They described *limitations* in HIV/AIDS education and prevention. HIV/AIDS services are limited to non-existent on reserve and often interview participants moved to large cities to access services away from their communities. They described *limitations* as affecting their ability to continue on their *Journey of Transformation*. Inabi recalled recent changes that he has noticed to services provided for HIV. He stated: "Now more than ever, the government is cutting back on services and supports for HIV positive

people on disability. Because it's a manageable disease. This has been implemented into the Canadian health care systems.”

Jacy described on her reserve there are places that services could be located to assist in the prevention of HIV/AIDS in her community. She stated: “There is nothing, no services on reserve. We need something. Anything. There are also no supports for staying clean, for the drug addicts. They need a 24-hour drop in centre to stabilize kids. There is nothing.” Makya expressed painful feelings when he recalled limitations in health care services he received in a small city in a prairie province when he accessed services for HIV. He stated:

Like every time I would get sick, I was so afraid to go in and seek medical attention in ... because of the way I was treated. I didn't want to have to go and battle with these people to get health care or to even get treated like a human being. The main reason why I moved back to ... was in...medical care treats you like a human being. You know they don't make assumptions. And they don't treat you differently because you are HIV positive. That's important.

Awan described limitations in services as the reason why he will not move back to his western prairie province. He stated: “My province only has one AIDS organization and Aboriginal and it is run out of somebody's basement. And if I move back, I'd probably not be able to get any disability. Like the same plan I have here. I wouldn't be able to live there and my meds wouldn't get covered either.”

7.1.5.3. Subtheme: *Aboriginal Service Provider*: A subtheme of *Aboriginal Service Provider* was identified within the theme *Services*. APHA interview participants shared the importance of having an *Aboriginal Service Provider* when accessing services for HIV/AIDS. Jacy indicated that for her, it was important to have front line service providers of Aboriginal descent. She stated that throughout her lifetime, it has always

been a challenge to build trust with people providing services and supports, due to the past barriers Aboriginal peoples faced within her northern community. She described the need for her community:

And it's got to be their own people. You can't send some white lady, up to the reserve and tell them. They are not going to listen. They got to be somebody like my mom, who speaks our own language. And talk to them in their own language and have a big feast, bring them all in. You know, something like that. But they don't do that, they don't think that way.

Lakota described it is important for APHAs to receive supports from someone who knows what it is like to be diagnosed. He stated:

That person has to be knowledgeable about what they are saying and doing. There is a real big distinction between HIV and AIDS. People should know what they are saying before they say it. I would appreciate another Aboriginal persons who has HIV/AIDS to tell me.

Makya described seeking out Aboriginal service and supports in the large western city where he lived and realized that there were limitations in finding an Aboriginal service provider. He decided then that he would create some. He recalled:

My life was in such chaos, it was just a mess. I wanted to have support from another APHA. And I realized there wasn't any. So I was going to have to do it myself. I had to start. I developed workshops that would help APHAs on their journey. Awareness about drugs, alcohol, the medicine wheel, all of that stuff. The healing work had to be done!

7.1.6. Theme: *Culture as Healing*: All participants described aspects of Aboriginal culture as essential in the process of living HIV positive throughout the interviews. The participants indicated that for them, levels of healing include connection to *culture*, which ultimately led them towards aspects of healing. The participants described numerous cultural aspects that have assisted them on their path to healing; culture emerged as being highly beneficial to those living APHA. Participants described culture as being a part of their journey of living APHA and often described it as a crucial aspect in identifying with

their HIV positive status. Some participants were not raised within Aboriginal culture and found that they wanted to learn about culture as adults. The main sub-themes that emerged from the analysis of interviews with participants were the importance of *validating traditions, cultural gatherings, elders and culturally safe counselors*.

7.1.6.1. Subtheme: *Validating Traditions*: A subtheme of *Validating Traditions* was identified within the theme *Culture as Healing*. APHA interview participants described how *validating traditions* was important for them as they navigated on their *Journey of Transformation*. Awan described having been raised within his Aboriginal community with his adopted extended family he had the choice of following the First Nations cultural teachings or following the teachings of Christianity:

I guess it was the way that I was raised. Like when I was growing up, my uncle and grandmother raised me. My uncle was the one who said, you can go to church with your grammas or you can come to the sweat with me, or you can go to school. I chose to go to school. So, I never had a chance to learn my culture, the cultural stuff, the sweats, and yes. That's why I don't do that now. I don't know how.

Esarosa described *validating traditions* and culture as an important aspect when he was learning to come to terms and cope with his APHA diagnosis. He had been disconnected from his Aboriginal background, as he was raised in a family where he was not encouraged to identify with his culture. He stated that over time, he began to investigate his Blackfoot roots, and this is where he finds much strength to assist in dealing with his APHA diagnosis:

I went back to school and we had to do a research paper about who we are, as a people. And what happened was, that's when I started talking to the grannies, the aunties, the uncles. That's where I found out that my grandfather was Blackfoot, from Blackfoot Nation, Montana. I kept researching and researching. Talking to our old people. I was talking to people that our family wanted nothing to do with. Then I started looking at how can I start honouring who I am as a First Nations person. How



can I know myself. So what I done was I started to see an elder. And then I met some elders in Hobema First Nations and then that's when I learned about my culture and my spirit animal. So that's who I am.

Guitan described how in his Aboriginal community and culture, a two-spirited individual was a part of the community; they were thought of as being very important to the community and accepted. He stated that once he started to learn this from the old people, he felt a great sense of ease and connection:

In Aboriginal culture, gay people were a part of the whole, the community. I started to find a place where I felt I belonged. And this new place that I belonged talked to my head, to my heart. Not just explanations to my mind. Although, they were there, right. In a deeper way. It all just changed significantly for me.

7.1.6.2. Subtheme: *Cultural Gatherings*: A subtheme of *Cultural Gatherings* was identified within the theme *Culture as Healing*. APHA interview participants described how *Cultural Gatherings* was important for them as they navigated on their *Journey of Transformation*. Makya identified the importance of spirituality and cultural gatherings on his *Journey of Transformation*. He Recalled:

I thought I knew about spirituality, just because I am Indian. And when I went to the gathering, I was accepted and I was taught. It was a valuable experience for me. I learned so much about my culture and now I know how to conduct ceremonies and do my healing.

Citali described a need for reconnecting with culture through gatherings. He stated: "I'd like to see spiritual gatherings. At more Aboriginal agencies. They don't have as many as they should." Dononma made the connection to her Aboriginal culture through cultural gatherings, through the work that she does as an advocate for APHAs. She had limited experiences growing up, as she and her mother had moved so often and she also experienced foster care. She stated

By attending the Aboriginal AIDS workshops, there was access for culture there. Cultural get-togethers. I learned how to make a rattle, from rawhide and shells. It was powerful. I began to realize my spiritual outlook, on my life. I opened up my eyes and I haven't looked back.

Esarosa described the importance of sharing information with other APHAs and is working towards hosting a cultural gathering. He recalled:

I want to be able to share, what I have learned. A give away, back to other APHAs. Like 'this is what I have learned, this is what I wanted to teach you. So you can teach others.' A gathering, where they will heal first. The family issues, then grieving issues. Get them to embrace who they are today. Using the medicine wheel method, with 15-16 APHAs, from different communities. SO they can take it back and do a workshop themselves, after they've learned and healed.

Citali described his experiences within the large eastern city where he lives as reminding him about the cultural practices from back home. He stated "It's good to see they are having groups for that. Spiritual healing. For sweating. For sweats. I have been to quite a few sweats. And the powwow. Spiritual support. Gives me hope." The interview participants described a number of ways that gatherings may assist in emotional health and well-being. They believe that culture is related and may assist in Aboriginal communities learning how to live with their diagnosis and continue to heal and become stronger. They are invested in the future and many dedicate their lives to improving the health of other APHAs.

7.1.6.3. Subtheme: *Elders*: A subtheme of *Elders* was identified within the theme *Culture as Healing*. APHA interview participants described how *Elders* was important for them as they navigated on their *Journey of Transformation*. Jacy described reconnecting with the old people in order to assist the younger Aboriginal youth to understand that there are cultural values and traditions that are alive and well in their communities. She indicated that building a stronger foundation of cultural knowledge

within her community on reserve, the youth would have a better chance than her generation did in the fight against HIV:

Reconnect with the Elders. Yes, feasts, giveaways and all of that. Gambling. Not bingo though, Teach then the traditional games again. You know, that's been lost. Simple little things. Like its summertime right now. Best time to go out and pick berries. Show them what kind of medicines there are. This is the time that you do all of this stuff. Have them prepare it. Give it to an Elder. Spend some time with them, with that person. You will learn something.

Citlali described accessing the Elders at an ASO in his city and indicated that this was ultimately the best support. He described having access to the elders as being culturally relevant, supportive and a strength that he accessed often. Citlali stated:

Accessing traditional supports help. Yes, they do, very much so. I find. I have a couple of elders that I see. And on a regular basis. That I usually confide in. If I am having a rough time, we usually talk it out. And we have our spiritual circle and sweet grass and all of that kind of stuff.

Jacy described the importance of accessing the elders in the community and suggested that all Aboriginal communities need to realize the importance of the wisdom of the elders. She recalled:

Educate the Elders [about HIV] and then the Elders can bring that information in to the families. The elders are the ones that everyone listens to. But it has to be an elder. That speaks our language and traditional ways. Bring them fish, moose meat, deer, whatever. Go into their homes. The traditional way.

7.1.6.4. Subtheme: *Culturally Safe Counselors*: A subtheme of *Culturally Safe Counselors* was identified within the theme *Culture as Healing*. APHA interview participants described how *Culturally Safe Counselors* was important for them as they navigated on their *Journey of Transformation*. Esarosa described the importance of those who provide services to be aware of culture. He stated “I use traditional medicines with

western medicines. I want my counselor to honour who I am as a person, a First Nation's person." Awan described the counseling services provided in the large eastern city where he lives as being culturally safe and he appreciated having the option to access a counselor that is experiences with Aboriginal culture. He stated: "I like the things that are offered here. They do a lot of cultural things. There are cultural councilors there. They provide traditional medicines, sweet grass. Its there and we smudge."

7.1.7. Theme: *Acceptance of identity*: Throughout the interviews APHAs described initial feelings of doubt and disconnection when they received their HIV positive diagnosis. Further analysis of the data revealed three subthemes that illustrated the *Journey of Transformation* that they experienced in regards to whether they were emotionally ready to identify with acceptance of an identity of a HIV positive diagnosis or not. The subthemes include: *denial and loss*, *acceptance* and *advocate*.

7.1.7.1. Subtheme: *Denial and loss*: The concept of denial and loss accompanied the HIV positive diagnosis with most of the APHA participants. Individuals shared experiences of denial and loss when they were diagnosed with HIV. Often participants buried their emotions in addictions, sometimes up to years at a time. For example, Donoma recalled: "...after I found out, that was when things kind of went bad for me, really kind of spiraled, into a very dark place and cocaine was my best friend." Jacy stated: "I went through quite a bit of depression and started using drugs and alcohol really bad when I found out." Guitan described life changing emotions, such as "feelings of total devastation, because once you're told your HIV positive, every part of your life changes, every part." As well, numerous participants recalled that at some point in the stages of denial, they had thoughts of suicide. Huyana recalled "Over that year, I kept

trying to commit suicide, overdosing and I was really, really lost.” Esarosa stated: “ I’m alone. I’m toxic. Nobody wants me. I’m going to die alone.” Donoma stated that having coming to terms with being APHA included becoming aware of the reality that she would die sometime. She was young and had not thought of the potential of dying.

Numerous APHA participants described initial feelings of denial and loss that accompanied their diagnosis. Feelings of loss were also associated with denial. Elsu described when he first learned his diagnosis; his first thought was that his partner would leave him. He stated: “I was crying, he was going to leave me because I am positive!” Awan stated: “ I just felt like hell, I didn’t know what to do or feel. Like who do I tell. I couldn’t sleep for two weeks. It really disturbed me!” Citali recalled: “It was very scary at first. How do I put it? It was very overwhelming emotionally.” Domona recalled a time in her life when she was in complete denial of the potential of being diagnosed with HIV, “I knew my partner had AIDS, but I didn’t go get tested. I was going crazy. Did lots of drugs and tricks. Stayed out on the street, just kind of went off the deep end, so to speak.”

7.1.7.2. Subtheme: *Acceptance of Diagnosis*: The second subtheme identified in the theme of *Acceptance of Identity* is *acceptance* of the HIV positive status. All of the APHAs described the various feeling associated with the HIV positive diagnosis, that ultimately evolved to their feelings of *acceptance*. Many of the participants expressed their initial feelings of anger, loss, embarrassment, shame and denial that eventually emerged into feelings of acceptance. Not all participants Journey of Transformation occurred in a similar time frame, as each individual took the time they needed to come to terms with the HIV positive diagnosis. However the feelings associated with the acceptance of their diagnosis were similar in nature.

Awan stated: “I was embarrassed, I knew how I got it through sex. And that shame. It was shameful. Like when I was growing up on the reserve, that if you become gay, you will get HIV. It was hard dealing with my diagnosis.” Over time, he stated that he came to accept the diagnosis and is an advocate in the fight against HIV/AIDS within Aboriginal communities. “I am an AIDS advocate. I go out speaking. That’s what I do.” Makya stated: “I had AIDS. Initially it was a relief because the game in my head could stop. The denial game. I would go from, I know I am positive, to, I am not positive. That denial game. I could stop running from it now.”

Guitan stated that when he first learned about his APHA status, he had already begun to walk on his healing journey from previous addictions. He stated that he had gained some tools and skills that he could access from addictions recovery that would help with emotional challenges of being APHA. He stated that he knew there would be challenges and he would adapt as he navigated his journey. Specifically, he stated he had hope for a time when he will be provided with an unconditional attitude if an APHA decides to disclose their status. Guitan recalled:

You see, the sooner we can normalize this, the better off everyone will be. There truly is no difference between diabetes and HIV other than, the unresolved sexuality issues and shame issues that people carry, right. I’d like to see a day where they are testing for HIV at powwows.

7.7.1.3. Subtheme: *Advocate*: The third and final subtheme identified was APHAs leadership qualities and advocacy. Most of the APHAs indicated that they were active in the APHA community and often advocate in their communities, as well as across Canada. For example, Awan stated: “ I do outreach, to crack kids, to homeless people. I help out. I’m an AIDS advocate. I like helping people.” Citali described seeing the atmosphere of education about HIV/AIDS change over time since he began advocating soon after he

was diagnosed. He stated: “In the past, I’ve done talks on the reserve about HIV/AIDS, so I am familiar with what the kids want to ask and stuff like that. I am more open-minded when I am talking about HIV/AIDS and my experiences now because things have changed over the years. Its good now. Was not good before.” Donoma described her advocacy role started once she had come to terms in acceptance of her diagnosis by becoming an advocate. She reported this assisted her in her journey to advocate for other First Nation’s youth to hear her story and make informed choices. Donoma stated: “as soon as people started hearing about this girl with AIDS, it just took off like wildfire. Everybody wanted me to go to their communities, so I did. I would go and talk to their youth, to whoever would listen and provide information and tools, giving basic information.”

APHA participants indicated that their life experiences have guided them to becoming who they are today, on their *Journeys of Transformation*. Many indicated that their lives changed when they received their HIV/AIDS diagnoses. However, there were numerous challenges that they had to tolerate in order to get on track with their healing journeys. They described how the supports that they accessed, formal or informal have assisted them to come to terms with their illness. Almost all of the participants who are APHA have been living with their diagnosis for more than ten years and described how with supports, an APHA has a stronger chance to embracing their illness and continuing on their *Journey of Transformation*.

Table 3: APAAs Four Themes

Propositional Theory	Themes	Subthemes
<p style="text-align: center;">A Journey to Psychological and Cultural Healing: Transformation of Identity</p>	<p style="text-align: center;">Psychological Experiences</p>	Shame/Fear
		Discrimination
		Anticipatory Grief
		Coping Strategies
	<p style="text-align: center;">Historical Traumas</p>	Residential School
		Multiple losses
	<p style="text-align: center;">Family and Relationships</p>	Foster care/Adoption
		Biological
	<p style="text-align: center;">Culture as Healing</p>	Elders
		Spirituality
		Retreats



7.1.8. Theme: *Psychological Experiences*: The first theme that emerged from the APAAs' interviews described *Psychological Experiences* as being important when they learned about their loved ones HIV diagnosis. Throughout the interviews the APAAs described the myriad of emotions that they experienced through learning about the diagnosis and how this impacted their lives on the path to the *Journey of Transformation*. In the grounded theory analysis, the subthemes of *Shame/Fear*, *Discrimination*, *Anticipatory Grief and Coping Strategies* emerged within the theme of *Psychological Experiences*.

7.1.8.1. Subtheme: *Shame/Fear*: The concepts of *Shame and Fear* were described by interview participants as being their first emotional reactions when learning about their loved ones HIV diagnosis. APAAs shared experiences of *Shame and Fear* when they learned of their loved ones diagnosis. Onida described how his family kept his sisters HIV diagnosis a secret and described that it was related to the shame that accompanies the diagnosis. Onida stated:

I guess we keep it [HIV] quiet. My dad wanted to keep it quiet. I guess he felt for my mom. I can't remember what his reaction was. We knew the drugs were always there and he kind of seen it coming. And it did...We haven't told anybody else about it in our family. Like it's just our close-knit family and we don't really tell anyone.

Aponi described how her family reacted when her brother was diagnosed with HIV. She recalled: "They stopped allowing him to come to the house. You know, every time he were to come around. It was like, come on lets go! Or my other brothers would take him away. Go drop him off somewhere else, away from the family." In Yotin's experience, she described having no one to confide in about her brothers HIV diagnosis. Her First Nations community has reinforced the feelings of shame that she has emotionally

endured since the community started to identify her brother as being an APHA. She recalled:

I was at the hockey game, my brother used to play, he was good too. And a friend said, 'too bad your brothers got HIV, he can't play hockey anymore because he'll spread it to the players.' I was hurt, ashamed and left. I won't go back to anymore games.

Aponi described feelings of fear when she learned about her brothers HIV diagnosis. She stated: "I have fear too. I'm wondering if my brothers okay. You know wondering if he's going to be all right. And that nobody's going to hurt him." Kachine described the fear that engulfed her when she went to see her twin, who was in late stage AIDS. She decided that she would not share her fear with him and she emotionally prepared herself to be strong for him. She recalled: "I walked over to him. All I could see was it was clear that he was dying. I looked at him and I could see the fear in his eyes. I thought, I cannot let him see what I am feeling, how scared I am right now!"

7.1.8.2. Subtheme: *Discrimination*: The concept of *Discrimination* was described by interview participants as being a part of the journey when their loved one was diagnosed with HIV. Kachine described how people started to treat her differently when they learned her twin was diagnosed with HIV/AIDS. "People were having a hard time with me. Even peoples response to me changed when my twin got ill. And I didn't get angry or upset. I was as confused as everybody else." Onida described a recent experience with discrimination when his niece, who had been diagnosed with HIV/AIDS and his family, had started preparing for her to enter kindergarten. He shared that his family was appalled at the discrimination they felt was directed at her when they contacted potential schools. He described how he was training to be an educator for children and he would never treat a child disrespectfully or discriminate because of an

illness. He described feelings of hurt and pain, for his family being treated unfairly and especially for his niece. He shared how he would have never expected such treatment from a school system in a southern Saskatchewan city. He recalled:

They wouldn't let her go to school because she was HIV positive. It was in the ...school system. And we tried to get her into school for awhile and they just said they wouldn't. They couldn't do it! So we couldn't find anything...My mom went down there and had an argument. It is just a little girl trying to go to school!

Paco who has been an HIV/AIDS advocate for over twenty years, described how her family experienced discrimination on the reserve because she chose to work with HIV/AIDS. She stated:

My dad was telling someone back home about the work that I do. It was supposedly a friend of mine. They were sitting down at the restaurant she asked my dad what I was up to. He said 'oh, she's doing a lot of work with AIDS in the community.' And he said, 'your friend just basically got up, pushed the table away and left.' Like why would she do that right!

7.1.8.3. Subtheme: *Anticipatory Grief*: The concept of *Anticipatory Grief* was described by interview participants as being a part of their emotional journey when learning about their loved ones HIV diagnosis. Aponi described how her father's misinformation about HIV has affected his feelings towards his son and she felt he was already preparing for his sons death. She recalled:

My dad is really harsh towards it [HIV]. And you know he doesn't understand it can be managed. I tell my dad 'you know he doesn't have to die. Its not like that anymore.' He says, 'he's going to die, we can't help him anymore.' He just wants no part of it anymore.

She described feelings of sadness and grief related to her brother's diagnosis, as she stated he has come so close to death over the past year. She recalled: "I know he can live having HIV. But he looks so sick now. He's not managing his pills. He also has mental

illness, and he is homeless. He could disappear and we wouldn't hear from him again. He'd be gone." Kechine's twin brother had been battling AIDS and had started to prepare his sister for his death. She described enormous growth between them during his final weeks of life. She recalled:

He was 70 pounds, lying on the couch, diagnosed with AIDS. He's isolated, devastated. I felt those feelings, because I was closest to him. I could feel his emotions, his pain I could feel his physical suffering of not being able to eat. I thought what did I do, creator. In that moment, to the best of my ability, I made a choice, to begin my own grief and grieving. And trying to deal with that for him. Not for me! But for him!

*7.1.8.4: Subtheme: Coping Strategies:* The concept of *Coping Strategies* were described by interview participants as being a part of their emotional journey when learning about their loved ones HIV diagnosis. Namid described as a child how she felt upset when learning about her mother's HIV diagnosis. She stated: "I guess you could say it [HIV] affected me in a negative way first. There was a lot of hurt and pain there because I didn't know what surrounded it. I couldn't be around her because she was sick." As she matured, she described building skills that assisted in managing the emotions. For example, she recalled: "To deal with HIV/AIDSs, you just have to do it. You have to cope with it all in different ways, spiritually, mentally, physically. In order to be able to handle it, not let it hurt you. Consume you." Paco described being an advocate in the journey of transformation takes a lot of psychological work. She described coping strategies as being a part of her journey. Paco stated:

The coping aspect, that's the challenge. And if people have a hard time seeing past the immediate, I think that's where we get lost. If you can actually imagine it, that this can be better! This can get better. I know it comes from the old words too. Like when we give up, we are lost. Our old teachings taught us to cope. We need to access these for HIV!

Yotin expressed limitations in her ability to cope with her brothers HIV diagnosis because she feels if HIV is not discussed, even within her own family, how can she manage her feelings. She recalled: “It’s like I am lying. Like it’s a something I’ve done. People look down on me. I just want to know where to start. How do I deal with this, when no one wants to talk!”

7.1.9. Theme: *Historical Traumas*: The second theme that emerged from the APAAs’ interviews described *Historical Traumas* as being responsible for their loved ones and their life circumstances. Throughout the interviews the APAAs described historical traumas that their loved one and themselves had experienced throughout. They described ways that this impacted them emotionally on their *Journey of Transformation*. Ultimately in the grounded theory analysis, the subthemes of *Residential Schools*, *Multiple Losses and Emotional Dysfunction* emerged within the theme of *Historical Traumas*.

7.1.9.1. Subtheme: *Residential School*: The concept of *Residential Schools* was described by APAA interview participants as being a part of their emotional journey. Aponi described the time when she and her brothers were driven to the residential school and how she described how she and her siblings felt abandoned. She explained:

I can remember my dad and my mom and my brothers and sister. And we all got put in the truck. We were driving up to this path, to a brown building. We were going up these stairs, then all of sudden me and my brother are being dropped off. And my mom was telling me ‘don’t cry, don’t cry!’ You know, ‘you have to stay. I couldn’t ask questions. I had to stay. I wanted to go home. We were left there, to get de-bugged and thrown in the shower!

Namid described attending residential school, which she recalled had occurred for many generations in her family. All of her kokum, mooshums, uncles,

aunties and her parents had attended. She described how attending the schools had resulted in disconnections in her family. She explained:

My mom got HIV and she went to residential school, so did my dad. They are both gone. I know that I have to learn to heal from the pain we have suffered. Residential schools took away the parenting skills and now I understand that there needs to be changes. We have to re-learn it.

Paco described how in her northern Alberta community, there are still generational effects that are in part results of residential schools. She has hopes that her community will learn to heal someday. She recalled:

The intergenerational piece, the residential schools piece. Three generations of chaos. If people don't find a way out of the chaos, those cycles, it just continues. The systems that were imposed on us, the child welfare act, residential schools, prisons, these are the Indian Act. They continue to undermine our capabilities!

7.1.9.2. Subtheme: *Multiple Losses*: The concept of *Multiple losses* was described by all APAA interview participants as being a part of their emotional journey. In the interviews, participants shared numerous events in their lives that likely have been impacted directly by the historical traumas that Aboriginal communities have endured. Aponi described how when visiting from residential school she witnessed the loss of her mother, through her mother's addictions. She recalled:

My mom, she was deceased in 99, when I was a child. I used to go and visit her. But my visits were spent in the kitchen, while she was in her room using. My dad also, he just drank, you know. Sometimes he sold pills and he ended up going to jail, doing some time. I grew up without my parents.

Kachine described the feeling of loss when her foster parents died suddenly, after being in their care for most of her childhood. She described:

My twin and I, we were 13 and both of our foster parents died. Within two weeks of one another. That was a lot. It was traumatic. I was just terrified. It devastated my spirit to have their death happen, this loss.

Namid described how at a young age she lost both her parents from injection drug use.

My mom died, I was 12 or 13 on the streets. My dad died a few years later. They were both heavy into the drugs. I admit! It was hard! I have dabbled a bit too. I was younger; I didn't know how to cope with death.

Onida described how his sister who is an APHA experienced numerous traumas in her life that have created emotional damage to his nieces and nephews. He stated:

My nephew was four or five and he came to us. He never talked. He just wouldn't. I know it was from the trauma of seeing the addictions and the partying, seeing something like that. Their dad passed away, he overdosed and then her next partner, he hung himself and I think he [nephew] was affected by that.

7.1.10. Theme: *Family and Relationships*: The third theme that emerged from the APAAs' interviews described *Family and Relationships* as important in their *Journey of Transformation*. Throughout the interviews the APAAs described the ways in which family provided them with unconditional love, strength and support. They also described ways that their life experiences of being in foster care and adoption assisted them in striving to find ways to break the cycle of foster care/adoption. In the grounded theory analysis, the subthemes of *Foster Care/Adoption and Biological Family* emerged within the theme of *Family and Relationships*.

7.1.10.1. Subtheme: *Foster Care/Adoption*: The concept of *Foster Care/Adoption* was described by all APAA interview participants as being a part of their emotional journey. In the interviews, participants described how experiences with addictions often resulted in kids being in foster care. Onida explained:

My mom couldn't, like we had three of my sisters kids already in my house and it was kind of hard on my mom. And my brother is on the same path as my sister. He's like a drug addict. It's just the same thing. His kids are in care too.

Aponi described her experiences in foster care as a time in her life where she is starting to work through the anger and pain. She recalled:

I still have anger, at being in care. And having my children taken away. Being a foster care survivor, you know and having my kids in care. There is a lot of stuff going on. And now, it helped me to understand that I don't want to live like that.

Kachine shared her experiences of being in foster care had effectively removed her and her twin from their biological connections. She recalled: "I was born in the east and was taken away, with my brother. We were raised in the concrete. I never adapted. I lost myself. Who I was. In foster care."

7.1.10.2. Subtheme: *Biological Family*: The concept of *Biological Family* was described by APAA interview participants as being important in their lives. Onida described how his siblings did not have contact with their biological dad and how important his biological dad's support was from him to make the right choices. He recalled:

I was kind of raised by both my mom and my dad. He's been there. He hasn't lived with us since I was seven or eight, but he's always been there every other weekend. He'd pick me up. Take care of me. He's always showed me the right path.

Paco described a time in her life when she was searching for her roots and was driven to seek out her family connections. She described how she had not had any contact with anyone outside of her immediate family and she was seeking connection to her heritage and family ties. She recalled:

I asked my mom, she was from boarding school and her mom had passed pretty young. And my grandfather had passed too. So I didn't have a lot of connection to that community. So I went and I found out. I met an auntie. I knocked on her door and she said, 'you are my granddaughter!' After that I went to her a lot about stuff in my life after that. When I had



an STD in the confines of marriage, I went to her. I talked to her about AIDS.

7.1.11. Theme: *Culture as Healing*: The fourth theme that emerged from the APAA interviews described *Culture As Healing* as important in their *Journey of Transformation*. Throughout the interviews the APAAs described the ways in which culture has been important in their lives. In the grounded theory analysis, the subthemes of *Elders, Spirituality and Retreats* emerged within the theme of *Culture as Healing*.

7.1.11.1. Subtheme: *Elders*: The concept of *Elders* was described by APAA interview participants as being important in their lives. Kachine described how she sought out cultural supports and indicated that the most effective supports were the elders. She recalled: “I would go where I could access the elders. Elders speaking. Elders Gatherings and I would always go sit with the elders. And I learned so much.” Namid described for her, elders are a requirement for all areas for Aboriginal peoples to heal. She recalled: “We have to have elders there. At the conferences. As Speakers. Have the elders teach everybody, so we can learn about our past.” Paco described how important it was to have elder guidance in her life and stated that the lessons she learned assisted her to have healthy emotions. She explained:

She gave me the okay to talk about abuses, addiction and about sexuality and helped me to understand some of the roles. There are a lot of women who are in situations that are not good. She experienced it and she’s an elder. So that’s my best support. She is my nohkum, she is the one who made it okay to get where I am today and dealing with this!

7.1.11.2. Subtheme: *Spirituality*: The concept of *Spirituality* was described by APAA interview participants as being important in their lives. Aponi recalled how her dad had created connection to their culture as children, even though it only occurred when she was home for visits from residential school. She reminisced a time in her life when they travelled to ceremonies. She recalled:

My family, when I was younger would go to ceremonies. My dad would load us up, when we went home for visits to the reserve. And we went to the reserves. My uncle would dance and we'd sit around. And have feasts and ceremony.

Kachine described how learning about her brothers APHA status led her towards healing and learning about her spirituality. She recalled: "I was starting to reach out for my culture. I went to a gathering and I did something for myself. I started to go away and do ceremonies."

7.1.11.3. Subtheme: *Retreats*: The concept of *Retreats* was described by APAA interview participants as being important. Aponi described being with other women who are APAAs as being emotionally fulfilling. She described: "I took part in a APAA group with other women and we'd talk about our issues in regards to addictions and social services. It was a support for me when I was dealing with so many issues." Kachine described having access to cultural support and attending traditional healing lodges as being fulfilling and supportive. She recalled: "I was at the traditional healing lodge. I was attending the healing circles, talking circles and they have elders in residence. That's where I had my first experiences. I go to the retreats every year and I fast."

#### 7.1.12. Theoretical Matrix

An image and theoretical matrix emerged from the voices of the APHAs and APAAs of a seed that over time may mature into flowering trees. These seeds, if

nourished and given a level of acceptance develop into new identities, just as seeds eventually grow into flowering trees. The tree symbolizes the life experiences, choices, challenges and lessons as well as participants accessing traditional Aboriginal teachings, illustrating ways that this has assisted each individual when making decisions whether or not to accept and identify with their new identity as an APHA or an APAA. For those who are not ready or willing to accept their diagnosis, the seed will remain in mother earth, in the soil, until a time when they are ready to accept and grow. The roots of the tree include core elements that emerged from data analysis, with each Aboriginal person experiencing movement throughout the growth of the seed to ultimately emerge and grow into a tree, if they have decided to accept their diagnosis or their loved one's diagnosis. This growth includes physical, mental, emotional and spiritual developments that ebb and flow throughout their *Journey to Psychological and Cultural Healing* and *Transformation of Identity*.

The *Journey to Psychological and Cultural Healing* is depicted as a flowering tree that grows from a seed from mother earth; different trees depict ways in which the life experiences of those who are APHAs or APAAs are unique. The tree is a sacred teaching that is linked to generations of knowledge keepers and storytellers within many Aboriginal communities. Goodwill (2009) described many teaching that included lessons that related to trees and how symbolically the tree represents an Indigenous worldview. His Dakota worldview encompassed many life lessons and values, which are also found in other Indigenous cultures. Lane, Bopp, Bopp, & Brown (1985) described ways that the elders who participated in a workshop in Alberta talked about sacred trees, describing the trees as representing healing, power, wisdom and security. The seed that eventually

matures into trees symbolically represent the theory, integrating the symbolism of the seed, roots, branches, leaves and flowers along with cloth and tobacco that hang from the branches. The seeds that eventually grow over time into trees emerged as a model of healing for those diagnosed with HIV/AIDS; this model may be utilized for Aboriginal individuals diagnosed with other chronic diseases and can be adapted for that purpose.

This model of transformation could be tailored and customized for treatment and interventions for Aboriginal individuals diagnosed with other chronic illnesses, such as diabetes or cancer. For those APHAs that are not ready to accept the HIV/AIDS diagnosis or may choose a life of addictions may not develop from a seed into a tree. These individuals who continue to struggle with addictions or are not ready to accept their diagnosis of HIV/AIDS will remain in the earth, as a seed, and likely do not develop into a flowering tree.

7.1.12.1. APHA/APAA: *A Journey to Psychological and Cultural Healing: Transformation of Identity*. The propositional theory *A Journey to Psychological and Cultural Healing: Transformation of Identity* suggests that APHAs and APAAAs are on significantly different journeys. As such, they will be discussed separately in this section.

7.1.12.2. APHA: *A Journey to Psychological and Cultural Healing: Transformation of Identity*. The APHAs described experiences of identifying with their illness after some time of adjusting psychologically and developing coping strategies as Aboriginal individuals who have been diagnosed with HIV/AIDS. An example of this is how they become open about their diagnosis over time. Eventually, most disclose their diagnosis publicly and often, most will share their life experiences with one another, family, friends, in public, at workshops and conferences. Although, it is important to note

that not all APHAs evolve through the process at the same rate of growth or at the same pace as other APHAs. For example, some APHAs will be in the process of building family relationships, or gaining psychological strength and growth and be a seedling. As the APHAs develop over time, most will mature into a flowering tree.

APHAs described their life experiences in this research often starting at the beginning, when they were diagnosed with HIV/AIDS. The historical traumas that they endured often resulted in them building and nurturing family ties and relationships. Some participants described knowing that they were HIV/AIDS positive and admitted that at that time they were not ready to get tested. They were at the stage of sprouting more roots and breaking through the soil to spring from mother earth and emerge as a sprout of a tree, as they navigated on their journey of attaining psychological strength in their journey of transformation. Over time, as the seed is nurtured, through aspects of supports, services and accessing culture as healing, the seed matures into a tree with branches and flowers that emerge to create the pods for the flowers. Over time, eventually the acceptance of identity emerges. The APHAs have completed this circle of their journey of transformation. They may also return to the journey and complete another cycle, as this journey of transformation can continue, as life does, full circle as a continuous journey in

In some experiences, an APHA may not evolve through their journey of transformation. Some reasons may include not being emotionally or psychologically ready to share their diagnosis, as they may not be in a place where they are on a journey to transformation. Other reasons they may not be on a journey of transformation may include dysfunctional relationships, risky lifestyle or addiction challenges. Ultimately,

this may result is denial of the HIV/AIDS diagnosis, where some APHAs may mask their feelings of doubt and fear, through denial, or addictions. Although, in this research, all of the APHAs described their experiences included strengths after much soul searching and developing feelings of acceptance of being HIV/AIDS diagnosed, they emerged as a seed that ultimately grew into a flowering tree as they navigated on their path of *transformation*.

The nature of acceptance throughout the APHAs journey emerged as a process of acceptance of oneself. That acceptance embraces the historical traumas, the diagnosis of HIV/AIDS and defining their relationship, which embrace all of their experiences in life, regardless if their experiences resulted in scars. Those scars are important for their journey of transformation and highlight those challenges that they have earned on their journey. Ultimately the APHAs have lived through historical traumas that have included experiences with residential schools, dysfunctional relationships and risky behaviors. These historical traumas resulted in assisting in the APHAs identifying with their transformation of identity, to an individual who is being perceived as an APHA, that highlights their perception of oneself, a flowering tree.

#### 7.1.12.3. APHA: *A Journey to Psychological and Cultural Healing:*

*Transformation of Identity. The Matrix:* A seed will mature and grow into a tree, which symbolizes the journey of APHAs who participated in this study (See Figure 1). *A Journey to Psychological and Cultural Healing: Transformation of Identity* includes a beginning, as a seed, from one of their ancestors. As the seed is nourished with earth and water, it develops into a seedling, breaking through mother earth to meet the sky and the roots spread out into mother earth. The seedling gains its strength by being nurtured

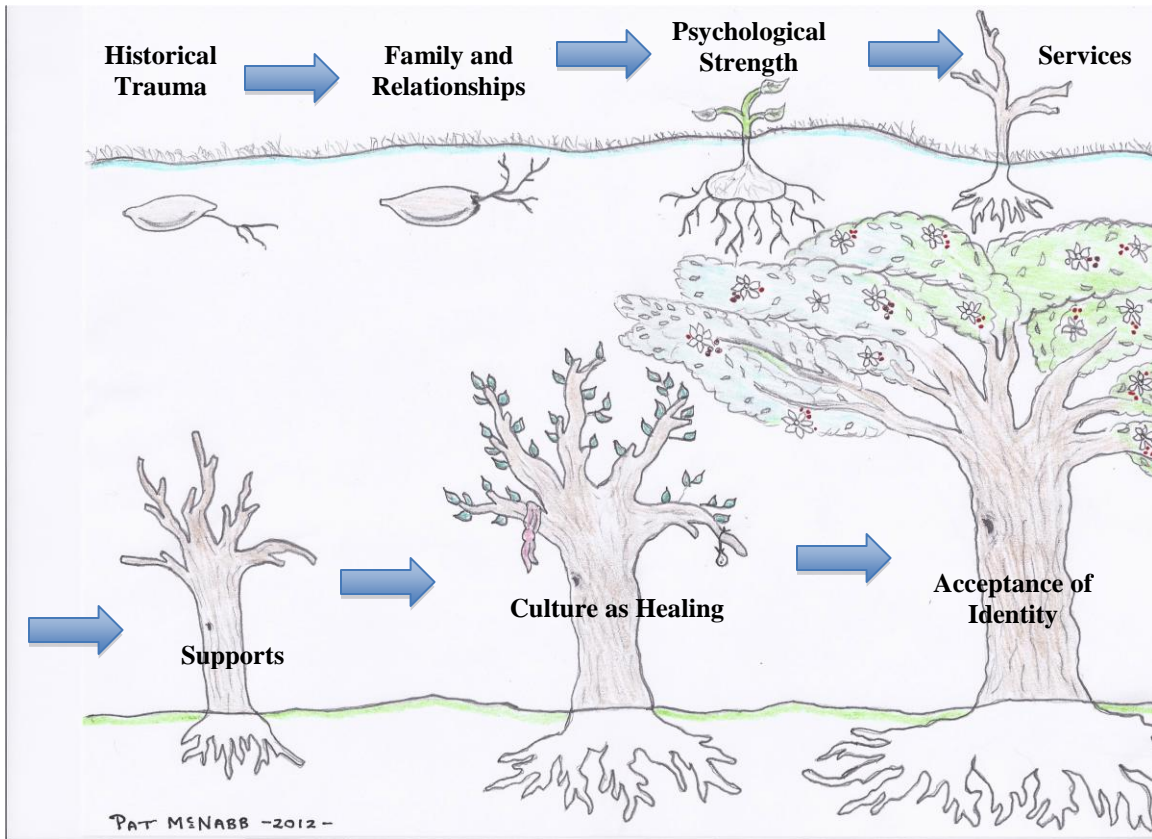
through emotionally addressing and coping with *historical traumas* that resulted from *colonization, sexism and racism*. On this journey of transformation, the seedling eventually gets stronger over the years, building physical, emotional, psychological and cultural strengths in *self-esteem, coping with stigma and discrimination, developing confidence, courage and resulting in resiliency*. Once the trunk begins to get larger in its growth, it develops branches, the aging/maturity process of transformation continues, with APHAs accessing *services and supports*. The branches of the tree grow and strengthen to include services and *accessibility, limitations and service providers*. As the years progress and the APHA continues on with their journey of transformation, the tree grows and becomes stronger. The branches develop into *supports* that include *peer-to-peer, APHA support groups, counseling services, education and engaging community members*. The tree trunk, branches and leaves symbolize their present lives, where they are in regards to their *Journey of Transformation: Psychological and Cultural Healing*. If and when they have come to terms with the emotional aspects of identifying with the diagnosis of HIV/AIDS and an APHA starts to embrace and accept, they engage in *culture as healing through validating tradition, cultural gatherings, elders and culturally safe counselors*. Eventually, the tree has matured over time and through their lifetime of personal experiences and growth as individuals with life experiences of coming to terms with their illness, they have sprouted flowers on the branches to signify their readiness to become the flowering tree and embrace their new identity. The APHA has evolved over time, to become a flowering tree, where emotional and spiritual *acceptance of identity* emerges. The APHA continues to grow and develop more branches and sprouts emerge and develop flowers growing from the branches. As the flowering tree matures and grows

over time and throughout their journey of transformation the APHAs become strong, rejuvenated individuals. The APHAs described life experiences that included numerous life challenges, dysfunction and risky lifestyles. They survived and emerged with a sense of purpose and knowing that their destinies included this journey. APHAs often described not changing anything in their past and believed their journeys are the way they were for a reason.



Figure 1. Theoretical Model of Aboriginal Communities Experiences of HIV/AIDS:

*APHAs A Journey to Psychological and Cultural Healing: Transformation of Identity*



#### 7.2.12.1. APAA: *A Journey to Psychological and Cultural Healing:*

*Transformation of Identity.* The APAAs described their experiences as being protective and secretive of their loved ones HIV/AIDS diagnosis. An example of this is how APAAs described rarely sharing with anyone that they had a loved one in their family/extended family diagnosed with HIV/AIDS. In this research, all of the APAAs stated that they had never shared that they were affected by HIV/AIDS with others, outside of their immediate family. They described feelings of guilt and pressure to keep the diagnosis private and secret. APAAs shared that very few people knew that their relative/loved one was HIV positive. In their interviews, the tone of their experiences came through in the interviews and often included feelings of anger, shame and frustration. Of significance, two of the participants had suppressed their feelings and emotions about their loved one who was an APHA. Both of their loved ones had passed away more 20 many years ago. During the interviews, both APAAs described sharing their life experiences of being affected by HIV/AIDS as empowering and fulfilling, as they felt it assisted in their journey of transformation and assisting in releasing feelings of guilt, shame and anger while describing what they endured as APAAs.

APAAs described their life experiences in this research often as protecting and hiding their loved ones HIV/AIDS diagnosis. The psychological and emotional experiences that they endured as they navigated the journey of transformations includes how their loved one who is an APAA came to identify with their illness. Specifically, if their loved one is not disclosing, they support their wishes. Another aspect is when the APHA does not want the support of their family or friends, which results in limited to no support for the APHA. Also, the APHA may have chosen to live a dysfunctional lifestyle,

such as taking risks with addictions or in denial of the illness. The APAA continues on their journey of transformation as they learn to navigate and adjust their life of providing supports and having a loved one diagnosed with HIV/AIDS.

In some experiences, an APAA may not evolve to mature into a flowering tree, or even reach the earth's surface. In this research, many of these participants had not shared their life experiences before and were unsure of when or if they would be open to sharing their experiences with anyone outside of their immediate family. Where the APAA felt they were on their *Journey of Transformation* was directly related to where they were in the progression through the emotions and feelings that they experienced by coming to terms with being an APAA. If they were not prepared to disclose that they had a loved one diagnosed, they did not reach the earth's surface which resulted in limitations of developing relationships and not seeking culture for healing.

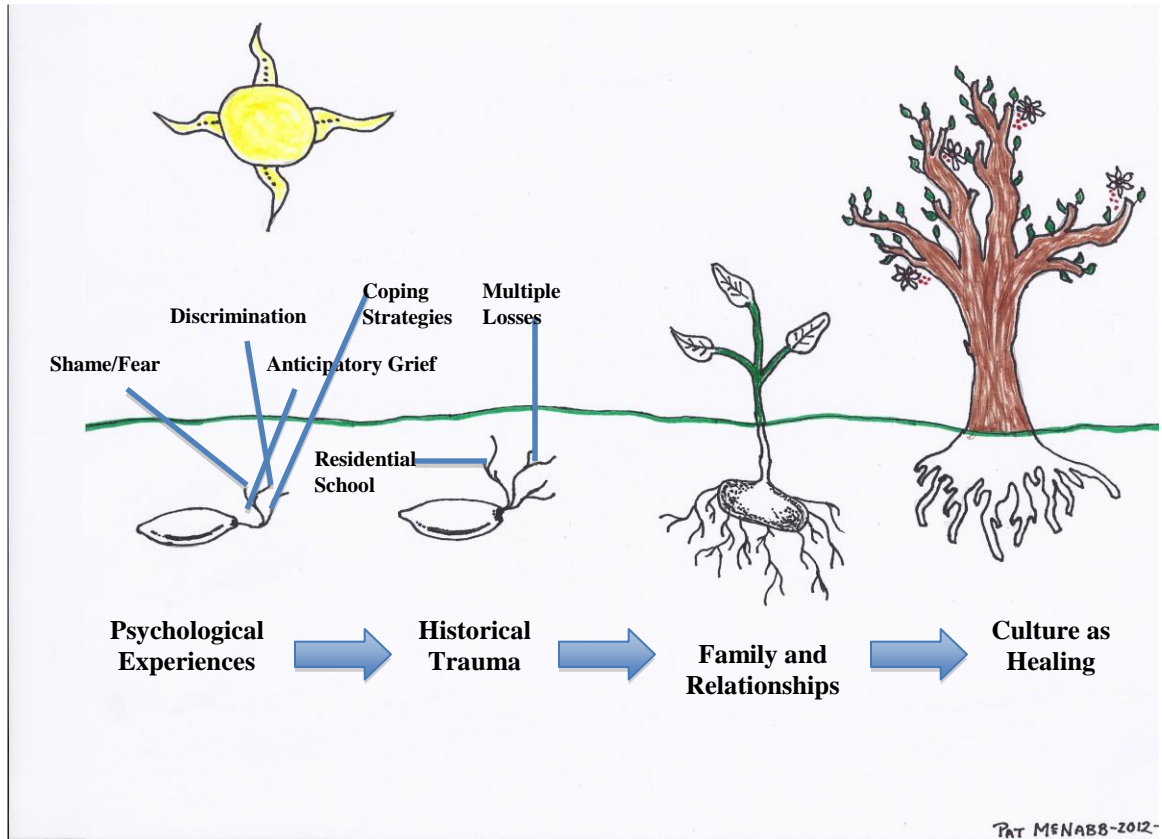
#### 7.1.12.3. APAA: A Journey to Psychological and Cultural Healing:

*Transformation of Identity: The Matrix:* The APAAs also begin their journey as a seed, from one of their ancestors, which symbolizes the journey of APAAs who participated in this study (See Figure 2). As the seed is nourished with earth and water, it eventually reaches the surface of the soil and ultimately develops into a seedling. The seed starts out in the earth and gains its strength by being nurtured through the psychological experiences of supporting their family member/loved ones HIV/AIDS diagnosis. On their journey of transformation, the APAA seed gets nourished and develops roots that shoot off the seed towards the earth. The APAA develops by experiencing their feelings and psychological experiences of *shame and fear, discrimination, anticipatory grief* and developing coping strategies. The seed's roots sprout a vine that grows towards the

surface and continues on the journey of transformation by building strengths and facing *historical traumas* that include *residential school* and *multiple losses*. On this journey, the seedling is reaching the surface when the APAA develops and strengthens family and relationships, through *foster care/adoption* and *biological* family ties. Eventually, the seedling has emerged on the surface and is developing into a flowering tree with its trunk and branches. As the branches develop, the APAA continues on their journey towards culture as healing by accessing *elders*, *spirituality* and *retreats*. The majority of the APAA's had not shared their stories before which ultimately affected the seed's growth and may have resulted in limitations of development, such that at times the seed did not break through the earth and did not fully mature into a tree. The seed remains in the earth in efforts to eventually to develop, build strength and awareness, resulting in a seedling that reaches the surface of the earth. Until that time, the APAA was stunted, slowing the growth of the seedling. As they came to terms with their feelings associated with being affected by HIV/AIDs, the seed had a chance to continue to grow and eventually reach the surface of the earth to develop into a flowering tree.

Figure 2. Theoretical Model of Aboriginal Communities Experiences of HIV/AIDS:

*APAAs A Journey to Psychological and Cultural Healing: Transformation of Identity*



7.1.13. The Invisible: In this study, life experiences of some APHAs and APAAs in Canada have been missed, from those individuals who could not speak to me as well as those who would never come forward to research. Other reasons may be due to psychosocial stressors and or individual factors. Additionally, addiction issues certainly had an impact on life experiences being shared in this study, as nine APHAs who had expressed interest in participating were unable to do so because of numerous missed appointments often due to addiction issues. These APHAs became invisible, as they could not be located to reschedule an interview. Researchers have identified that within HIV/AIDS and Aboriginal people, there is often a population that is missed in research due to numerous factors, such as poverty, transiency, addictions, mental health issues, etc. (Ship & Norton, 2000; Prentice et al., 2011). Potential participants in research studies remain hidden in the HIV/AIDS epidemic within the Aboriginal population in Canada. As a consequence, we have much to learn about those individuals who are invisible who have been diagnosed with HIV/AIDS in the Aboriginal population. The invisible individuals are depicted in the model as a seed, that may eventually grow and move along in the journey of transformation, if they chose to work towards identifying as a APHA.

## 8. DISCUSSION

### 8.1. Overview

My interest in researching HIV/AIDS within Aboriginal communities emerged from my own personal experience, when my sister was diagnosed with HIV/AIDS. I began investigating HIV/AIDSs within the Aboriginal population in Saskatchewan, focusing on Aboriginal women. I decided to develop a qualitative study for my PhD and focused on men, women, youth and elders within the Aboriginal communities across Canada to understanding their life experiences when diagnosed with or having a family member diagnosed with HIV/AIDS. The prevalence of HIV/AIDS within the Aboriginal population in Canada is currently estimated to be 4,300 to 6,100 individuals living with HIV (2010, PHAC). However, these statistics do not portray the full picture of how Aboriginal communities are affected, as not all provinces report ethnicity. The impact that this illness currently has within many Aboriginal communities in Canada is resulting in profound and devastating effects emotionally, mentally, physically and spiritually.

The purpose of this present study was to gain a better understanding of HIV/AIDS by asking interview participants about their life experiences being Aboriginal individuals who have been diagnosed with HIV/AIDS. I was also interested in gaining a better understanding about the experiences of Aboriginal community members whose loved ones/relatives have been diagnosed with HIV/AIDS (those affected by HIV/AIDS). Finally, I wanted to understand what recommendations/guidance the interview participants could provide for Aboriginal Peoples and HIV/AIDS that would assist this researcher in developing a culturally-relevant psychological theory that will assist with

healing. Twenty Aboriginal Canadian participants participated in a qualitative open-ended interview.

The theory that emerged from the data is a process of growth that an Aboriginal individual might experience when diagnosed or affected by HIV/AIDS. The participants in this research are made up of a unique group of Aboriginal individuals in Canada and represent the experience of a portion of the population. The majority of the participants in this research were accessing support and services provided by AIDS service organizations. In fact, ethically, this is the only way I felt that I could recruit participants. Therefore, it is important to keep in mind that there are many other life experiences out there in Canada that have not been heard. Specifically, in my research, nine Aboriginal individuals expressed interest in participating. Unfortunately, life circumstances prevented them from participating. Recently, I learned that one of the potential participants for my study passed away. I am saddened by her loss and will continue on with this work because voices in our Aboriginal communities in Canada need to be heard.

The APHA participants' descriptions of their life experiences and journeys resembled parts of the theory that I discovered in my previous Masters thesis with Aboriginal women and HIV/AIDS, where they are *walking on a journey on the path to healing* (McKay-McNabb, 2005). I was cognizant of fact that my dissertation research was not only about Aboriginal women, as it was about being more inclusive of the Aboriginal communities. I made every effort to ensure that I put aside the theory that emerged from my Masters thesis with Aboriginal women. However, as the writing progressed, I did realize that there were a few similarities. One of the similarities was that the Aboriginal community members who participated in this dissertation research suggest



that they have been walking a journey to the path to healing and they are at different stages of healing and growth. Specifically, some APHAs have been living with HIV/AIDS for over twenty years, and were open to sharing their life experiences since the beginning of their diagnosis. Alternatively, APAAs who had a family member or loved one diagnosed, sometime over twenty years ago, had not shared their life experiences with anyone prior to their participation in this research. Most importantly, there were clear distinctions between the two research studies I conducted about HIV/AIDS in my Masters and PhD. Specifically, they differed in regards to the theory. In this research, the theory that emerged resulted in two propositional theories about Aboriginal communities and HIV/AIDS for APAAs and APHAs. In the following section, I will explore the themes that arose from the interviews in the context of previous research findings. It is important to note, that I have yet to locate a previous study in Canada conducted with APAAs and there are very few articles about APHAs. Therefore, the results of this research will add to the paucity of literature that is currently published about Aboriginal communities in Canada and HIV/AIDS.

## 8.2. The Matrix

The matrix of the theory of *A Journey to Psychological and Cultural Healing: Transformation of Identity* resulted in the image of a seed. The matrix related to the teachings I have received throughout my life from oral stories and ceremonies. For example, Elder Ken Goodwill shared traditional stories with me about how trees symbolize life and is significantly connected to many of our traditions, ceremonies and cultures (personal interview, November 2007). He described significant lessons that included a teaching about our spiritual and cultural relationship with trees. Many of these

teachings have guided me on this journey in academia and in life. Trees often represent and signify medicines and ceremonies for many Aboriginal peoples. Elder Betty McKenna described trees as symbolizing life, the fire as representing life; fire burns from the wood of the trees (personal interview, March 27, 2012). Trees have been described as symbolizing transformation, with the root of the plant emerging from a seed and representing the connection to the past; trees honor our heritage and our ancestors. The tree trunks represent the present, revealing the life force and creative spirit within each of us. Branches represent individuals' future goals, as they emerge from the trees trunk and reach towards the sky. The leaves symbolize attainment of goals and rejuvenation. The leaves are consistently changing as the season's change, just an individuals does throughout their stages of development in life. Each of the trees that have been created as a matrix depicts the emerging theory, starting out as a seed of our ancestors and growing and maturing into a flowering tree: *A Journey to Psychological and Cultural Healing: Transformation of Identity*. The visual depictions include the transformation that an Aboriginal individual experiences when living with their HIV diagnosis or being affected by HIV (see Figure 1 and 2).

### 8.3. Transformation of Identity

Researchers suggest that the colonization of Indigenous Peoples resulted in numerous challenges and these negative effects have impacted many Aboriginal communities in Canada (Anderson, 2000; Chrisjohn & Young, 1997). Profound changes occurred within the context of mental health and identity within the Aboriginal population in Canada as a result of colonization; these changes continue to impact our communities today (Kirmayer, Tait & Simpson, 2009). Kirmayer and colleagues (2009)

suggest that extreme transformations of identity within many Aboriginal communities in Canada have been linked to high rates of depression, alcoholism, violence and suicide. It is important to note that not all Aboriginal communities have these challenges and many are doing well. The notion of transformation is a process where an individual constructs their identity from their current situation, often by accessing their cultural and ethnic roots; development of their identity is often an ongoing construction, that is often contested from within and from without (Kirmayer, Tait & Simpson, 2009). In this research, transformation of identity is described as a process where the individual accesses and develops their internal and external self through the psychological and emotion acceptance of the HIV diagnosis or their loved one's HIV diagnosis. Kirmayer and colleagues (2009) suggest that for many Aboriginal peoples, relationships emerged from that culture of individuals to be appreciated as a co-creation by people in a response to current circumstances as on an ongoing construction.

Erikson's (1968) theory of identity development suggests that individuals experience eight stages of development that emerge through experiences of conflict, where there is a potential resolution where the identity can be polar opposites. Erikson suggests that an individual must experience both sides of the conflict; when they do, they move onto the next stage. The nature of the "social crisis" is provided with a name, that results in its progression throughout psychosocial stages. The eight stages include: trust vs. mistrust; autonomy vs. shame and doubt; initiative vs. guilt; industry vs. inferiority; identity vs. identity confusion; intimacy vs. isolation; generativity vs. stagnation and finally integrity vs. despair (Erikson, 1968). Erikson described the process of growth toward a positive self-concept as being directly related to the psychosocial stage

resolution. Alternatively, if the individual does not resolve the conflict or it persists over time, the individual will experience a negative quality that is then integrated within their personality structure. The notion of identity in my research integrates Erikson's theory of identity with links to the stages of "the rapids of life" that Elder Betty McKenna described, as stages of development, where an individual's identity may remain stagnant and this lack of movement may result in stunting their psychological growth as an individual. The APHAs and APAAs in this study navigate through various stages when and if they decide to identify with being diagnosed or a loved one being diagnosed with HIV/AIDS.

#### 8.4. Historical Traumas

Duran and Duran (1995) identified a model of six phases of colonization that may result in negative psychological reactions within colonized peoples; this negative psychological reaction is called "historical trauma": The six phases of colonization identified by Duran and Duran (1995) are: historical trauma. They suggest that there are six phases that resulted from colonization: 1) First Contact, 2) Economic Competition 3) Invasion War Period 4) Subjugation and Reservation Period 5) Boarding School and 6) Termination Period. They suggest that each phase is interconnected to experiences in other stages such that when trauma is experienced in any one phase it is linked and interconnected to the trauma in other phases of the atrocities of colonization perpetuated towards Indigenous Peoples. Their model is similar to Brave Heart's (1995) model that describes how colonization creates emotional turmoil and ways this is related to historical trauma within Native American communities.

Brave Heart (2003) defined Historical Trauma (HT) as a cumulative emotional and psychological wounding across the lifespan and across generations that results from massive group trauma. The concept of Historical Trauma within the Native American population emerged in the mid-90s in the medical and psychological literature (Brave Heart, 1998). The concept of HT includes lifespan trauma in a collective and historical context that includes communal and individual trauma of Indigenous survivors of colonization.

Yellow Horse Brave Heart, Chase, Elkins and Altschul (2011) investigated intergenerational group trauma with Native Americans by utilizing the Historical Trauma scale (HTS). They intend to develop various trauma scales to further investigate Historical Trauma in order to create and develop interventions to assist healing the collective intergenerational group trauma that resulted from European contact with Native Americans. These newly developed measures are meant to assist in creating interventions that may be adapted for specific cultural groups, such as Dakota and Lakota peoples. Their findings indicate that there is a paucity of research within the Indigenous population in the United States in regards to Historical Trauma. Although, in regards to mental health previous studies indicate that American Indians and Alaskan Natives have elevated levels of Post-Traumatic Stress Disorder (PTSD) and depression. This is mirrored within the Aboriginal population in Canada who suffer elevated depression and other mental health problems (Prentice et al, 2009; Waldram, Herring & Kue Young, 2006; Brasfield, 2001).

The APHAs and APAAs who participated in this research described experiencing a variety of historical traumas. Researchers suggest that collective emotional and

psychological injuries have occurred over the lifespan and for generations amongst Native Americans resulting from colonization (Yellow Horse Brave Heart, 2009). Yellow Horse Brave Heart (2009) identified six phases that occur in the development of historical trauma in individual's psychological response to colonization; in each stage she identified specific emotions that an individual experiences.

Essentially, the six phases of historical trauma described by Yellow Horse Brave Heart (2009) relate to the experiences that the APHAs and the APAAs described in the interviews. Many participants described levels of historical trauma that explain why there is disconnection within their families. When they were able to identify that there was a link to historical trauma and their current life circumstances, participants were able to grow. Specifically, understanding the link between historical trauma and their present life experience assisted participants to gain a better understanding about how colonization, sexism, racism, residential schools and multiple losses had effects on their lives. For example, both APHAs and APAAs described how they came to an understanding that historical traumas had an impact on their lives and how many are working towards challenging the generational traumas in hopes to strengthen their lives in the future.

The legacy of federal and provincial policies and the forced assimilation within many Aboriginal communities resulted in dysfunctional relationships (Kirmayer, Tait & Simpson, 2009). Results of the dysfunctional relationships created by these policies have emerged as mental health consequences within many Aboriginal individuals. The policies and forced assimilation resulted in effectively challenging individual and collective personal growth and well-being ultimately resulting in everyday problems in living and mental health disorders such as anxiety, depression and posttraumatic stress disorder

(Kirmayer, 1994; RCAP, 1996). Consequently, there has been a systematic devaluing of Aboriginal identity by mainstream society that has occurred for generations and this devaluing (or racism) has created tremendous barriers for many Aboriginal peoples; barriers to creating positive identities and for resolving historical trauma. Psychological interventions are urgently needed to assist individuals to re-build their identity, to foster positive self-esteem and nurture a positive collective community. A first step toward this positive move has been suggested by researchers and it is to deconstruct the systemic, political devaluing of Aboriginal identity (Kirmayer, Tait & Simpson, 2009).

Hill, Lau and Sue (2010) suggest that interventions integrating trauma psychology with cultural psychology should be considered in regards to the treatment of historical trauma. Specifically, they posit that Indigenous perspectives informed by historical, cultural and epistemological standpoints are uniquely positioned to provide a transformational framework, redirecting the process and impact of integrating cultural psychology with trauma psychology (Hill, Lau & Sue, 2010). They suggest disassembling the dominant western theoretical assumptions in regard to treatment and interventions and building relationships and developing a collaborative dialogue when developing assessment and intervention tools to assist in addressing historical trauma. Their recommendations for interventions are similar to Yellow Horse Brave Heart, Sue and Sue and Duran and Duran, where it is of the utmost importance to facilitate trauma interventions and treatment plans within a collaborative, collective transformational framework. Furthermore, the theoretical model that emerged from the APHAs and the APAAs in this research may be utilized in the future to assist in building interventions and strategies for treatment of other chronic diseases, such as diabetes.

For many of the APHAs and the APAAs, resolving historical trauma involved becoming aware of how their lives had been affected by colonization, racism and sexism. For a number of the participants, this process began when they had gained a better understanding about how their lives and their families had been purposefully devalued, to ultimately change their way of life. Once they had come to terms with the historical traumas, they were better equipped emotionally to continue on with their journey of transformation.

#### 8.5. Family and Relationships

All APHAs and APAAs who participated in this research described experiences with family and relationships that facilitated both positive and negative experiences. Specifically, numerous participants were raised in foster care, adopted or attended residential schools, which were both positive and negative experiences for them. They described how some relationships facilitated their growth as individuals and others resulted in dysfunctional relationships. Barlow (2003) indicates that many Aboriginal communities who experienced residential schools resulted in displaced roles in parenting and sibling relationships. Furthermore, he suggests that residential schools have impacted the connection to family and community and engaging in negative coping patterns, including substance abuse.

Research suggests that families who have a parent or child infected with HIV/AIDS experience feelings of denial, concealment, isolation, sadness and cope through support from family and friends, reordering priorities for relationships and drug use, and problem-focused, emotional focused strategies (Rehm & Franck, 2000; Gillman & Newman, 1996). Furthermore, Rehm and Franck (2000) suggest that family's



responses to an individual diagnosed with HIV/AIDS within their family are similar to coping strategies that are used for other chronic diseases. Currently there are limitations in the literature about family coping strategies and HIV/AIDS.

Researchers have identified family responses to chronic health conditions which suggest that the process of normalization of the chronic illness along with behavioural strategies provide supports to family members with a chronic health condition (Deatrick, Knafl & Murphy-Moore, 1999). Attributes of normalization described by Deatrick and colleagues suggest that families may access the following to assist in normalization of a chronic health: 1) acknowledging the condition and its potential to threaten lifestyle, 2) adopting the normalcy lens for defining family, 3) engaging in parenting behaviours and family routines that are consistent with the normalcy lens 4) developing a treatment regimen that is consistent with a normalcy lens, and 5) interacting with others based on family as being normal. Although, from the results of this current research study, the process of normalization may result as a challenge, as many participants have not had the life experience of normalization in life, let alone dealing with the challenges and psychological problems that accompany a chronic illness.

Nöstlinger, Jonckheer, De Belder, van Wijngaerdenm Wylock, Pelgrom and Colebunders (2004) investigated caregivers of HIV affected families and the emotional burden that it carries. Their findings suggest that discrimination was identified as being the major obstacle to prevention and care of their loved ones who are diagnosed with HIV. The results indicate that silence about the HIV diagnosis within the family results in extending stigma onto the next generations and emotionally burdening the HIV diagnosed caregiver and the HIV affected children. Furthermore, the results suggest that

the caregivers struggle with emotions and coping with their HIV diagnosis accompanied by the chronic illnesses health consequences. Suggestions of intervention strategies include integrating a family perspective into the psychosocial support of caregivers living with HIV, being tailored and culturally sensitive and utilizing a model of good practise that have been identified in other chronic diseases, such as in Cancer and Diabetes.

#### 8.6. Support

Participants described the importance of supports and services as they came to terms with a transformation of identity being an APHA or an APAA. Research suggests that social support is defined as a multifaceted concept that includes ways that an individual's well-being and coping are improved by involvement in social networks, the perceived availability of help and acceptance of others, or the exchange of tangible and symbolic supports in interactions between people (Albrecht & Goldsmith, 2003). APHAs described when they were a part of a group or a network they were more open to developing coping strategies and techniques. Alternatively, most APAAAs were not willing to access support groups and were more likely to have psychological limitations in regards to coping mechanisms.

Friedland, Renwick & McColl (1996) examined coping, social support and quality of life issues among people diagnosed with HIV/AIDS. They suggest that the availability and utilization of support from family and friends has a significant impact on their overall well-being. The respondents strongly indicated that they wanted access to more emotional supports. Additionally, practical and emotional support, which primarily came from lovers/spouses, was reported as being helpful. Most importantly, the respondents indicated that they had limited access to emotional support, financial aid and

spiritual support with family providing limited support (Friedland et al., 1996). Previous studies indicate that people with HIV/AIDS are often alienated, emotionally and geographically from the natural support groups – their own families, who should be providing support (Turner, Hays & Coates, 1993). The APHAs described being strongly connected to other APHAs when it came to seeking support. Most participants in this research, if they had access to an APHA group, described being provided with unconditional support and feelings of connectedness. This was beneficial for emotional well-being and ultimately had positive effects on their overall health and wellness.

There are increased demands on caregivers with already limited resources for those who are supporting an APHA or an APAA. This increased burden impacts the limited social support networks. Research indicates that enhanced social support increases adherence to treatment as well as health service utilization (Knowlton, Hau & Latkin, 2004; Takahashi & Rodriguez, 2002). Ciambone (2002) suggests that higher levels of life satisfaction and quality of life are associated with social supports being available to people diagnosed with HIV/AIDS. Research has indicated that social support is an important factor in easing the stresses experienced by people living with HIV/AIDS (Serovich, Brucker & Kimberly, 2000). The APHAs and APAAs would certainly benefit from social supports if they were available in many ways, including mentally, physically, emotionally, and spiritually.

#### 8.7. Support and Coping

APHAs and APAAs described that having access to supports was beneficial to their journey of transformation. Ultimately, different types of support are required in varying combinations at different stages of living with HIV/AIDS. These supports may

include informational, instrumental and emotional. Researchers have indicated that types of social support have been associated with reduction in depression. Informational support was identified as being especially helpful in the early stages of coping with a chronic disease (Prentice et al., 2012; Freidland, Renwick & Mccoll, 1996). Accessing and receiving social supports when diagnosed with HIV/AIDS requires a process of disclosure. Research identified that there are significant considerations an individual has to come to terms with when deciding to disclose; these may include challenges and difficulties, such as adverse social consequences (i.e., rejection, abandonment or assault) (Bharat, 1996).

APHAs who are living with a chronic illness and diagnosis often experience feelings of uncertainty. Feelings they may experience include uncertainty about their prognosis, potential treatments, social relationships and development of identifying with their illness. Brashers, Neidig and Goldsmith (2004) suggest that support from others helps people with HIV/AIDS to manage uncertainty. Specifically, their findings suggest that assisting with information seeking and avoiding, providing instrumental support, facilitating skill development, giving acceptance or validation, allowing ventilation and encouraging perspective shifts, will create a foundation to build coping skills to deal with an HIV/AIDS diagnosis. Furthermore, individuals living with HIV/AIDS experience uncertainty because of the unpredictable progression of the disease and the myriad of symptoms and reactions that the disease may entail. Brashers and colleagues (2004) identified that communication with a support network was a valuable part of uncertainty management and developing strategies for managing dilemmas. Research suggests that APHAs and APAAs would benefit from building coping skills to assist with addressing

the emotions related to coping with an HIV/AIDS diagnosis. The theoretical model that emerged from this study identified support and coping as being a process in their journey of transformation.

#### 8.8. Disclosure

In this research, the results and the model suggest that many APHAs described their individual experiences of disclosure as having a strong influence on their journey to transformation. Some APHAs described experiences of betrayal and broken trust when a relative decided to expose their illness before they were ready. Alternatively, some APHAs described keeping their HIV/AIDS diagnosis a secret for years, ranging from two to twenty five years. Ultimately, how an individual discloses their HIV status has emotional connections that may influence their well-being and it certainly can result in feelings of loss and devastation and for some it results in an eventual identification with the chronic illness. Kalichman, DiMarco, Austin, Luke and DiFonzo (2003) suggest that the majority of individuals who are going to disclose their HIV status do so with friends significantly more often than family. Additionally, participants that had disclosed to immediate family members (i.e. parent, sibling) reported more social support from those relationships and that this social support may reduce emotional distress in people living with HIV/AIDS. Kalichman and colleagues (2003) further suggest that there are feelings of perceived stress associated with disclosing HIV/AIDS in regards to social support. Most importantly, their findings suggest that people diagnosed with HIV/AIDS who have lower levels of social support tend to have depressive symptoms.

#### 8.9. Peer-to-Peer Support

All APHAs and APAAs indicated that peer-to-peer support was effective in relaying information about treatment and prevention of HIV and AIDS within the Aboriginal communities in Canada. Peer support has been noted as being effective and useful for those who are HIV/AIDS positive. Results of Brashe, Neidig and Goldsmith's (2004) research suggests that peers provide support which assists in managing personal, social and medical aspects of living with HIV.

Roy and Cain (2010) indicate that peer education by someone who is infected is widely seen to assist in bringing HIV/AIDS experience "close to home" and has a greater impact on audiences in regards to education and awareness. Furthermore, clients who access services and support indicate that they prefer receiving supports and services from people living with HIV/AIDS. Clients identified not being judged and that they talk more freely with a peer. Rapport building was also identified as being built quicker with a peer counselor than with a person who is not HIV positive (Roy & Cain, 2010). APHAs and APAAs identified in this study indicated that they felt stronger connections to other who are living with HIV or affected by HIV.

#### 8.10. Gender and Support

Aboriginal women face numerous barriers when deciding if and when they will access formal supports. Specifically, Bucharski, Reutter and Ogilvie (2006) findings suggest that Canadian Aboriginal women reported a number of barriers in seeking HIV testing. Barriers included being judged unfairly by others, shame, perceived lack of anonymity, fear of testing positive and being judged by their own people. Broader systemic barriers were also reported as a lack of trust resulting from colonization experiences, institutionalized discrimination and child welfare involvement (Bucharski et

a., 2006). The Bucharski et al (2006) study identified that a significant key component to culturally appropriate care for Aboriginal women and HIV/AIDS was understanding of historical, past and present life experiences of Indigenous peoples when providing supports and services. APHAs and APAAAs also identified having culturally safe support as important when accessing support and services.

Aboriginal women are often the caregivers and nurturers within the family and are responsible for the care of their children and families (Ship & Norton, 2000). The ability to provide for their basic daily needs, along with their children and family are often a struggle for low-income single mothers living with HIV/AIDS. Also they have few resources, if any, in regards to emotional and social supports. Furthermore, Aboriginal women face disadvantages in regards to gender disparities, discrimination, racism and socioeconomic conditions that impedes access to medical and social services and supports that could enhance their own and their families well-being (Ship & Norton, 2000; McKay-McNabb, 2005). Many APAAAs and APHAs women in this study may not have been able to participate in this study due to their responsibilities as caregivers. For those that did share their life experiences, they did express the importance of their roles as the caregivers and how their families were a priority often over their own needs.

Psychological adjustment has been identified within women with HIV/AIDS as important for their ability to develop supportive relationships. Schrimshaw (2003) investigated whether the source of unsupportive social interactions within a diverse group of women with HIV/AIDS had effects on their psychological adjustment to their illness. Findings indicate that psychological adjustment to HIV/AIDS and unsupportive social interactions result in negative effects on depressive symptoms (Schrimshaw, 2003). Most

importantly, unsupportive relationships with family members are challenging to deal with emotionally, as family members are often living close by and the women rely on them for practical and financial assistance in their day-to-day lives. APHAs and APAAs in this research identified having experienced depression in their lives; two participants indicated having experienced numerous episodes of clinical depression. Interview participants identified that it was important to have supportive relationships and stressed the need for more culturally appropriate services, supports and counseling, which could enhance their own and their families well-being.

#### 8.11. Aboriginal Youth and Support

Aboriginal youth have challenges when accessing health care that are unique based on their socio historical position in Canadian society (Larkin, Flicker, Koleszar-Green, Mintz, Aagnino, M. & Mitchell, 2007). Prentice, Mill, Archibald, Sommerfeldt, Worthington, Jackson and Wong (2011) surveyed Canadian Aboriginal youth to gain a better understanding about accessing HIV testing and care services. Their findings suggest that youth tested late in the course of the disease, which is consistent with previous findings. Additionally, these youth delayed seeking care for more than a year following an HIV diagnosis. Most importantly, Aboriginal youth indicated that they would prefer to access services if they were provided a number of needs in one place and support from friends, family and others as an important motivator for Aboriginal youth to initiate care and treatment for HIV/AIDS.

There is an overrepresentation of HIV/AIDS among Aboriginal youth within Aboriginal communities, as HIV/AIDS test reports indicate that they make up 19.3% of reported AIDS cases in Canada (PHAC, 2010). Currently, there are a few projects that



have been initiated for Aboriginal youth in Canada to address the alarming rates of HIV/AIDS within the Aboriginal youth population. Specifically, a group was created to address concerns from a youth lens, National Aboriginal Youth Strategy on HIV/AIDS in Canada (NAYCHA) (Yee, 2011). This youth group is guided and driven by, with and for Aboriginal youth in Canada to address lowering the HIV infection rates. APHAs and APAAs in this study identified that it is important to engage Aboriginal youth in this fight against HIV/AIDS and Aboriginal communities because of the rising rates. In time, NAYCHA may have implications on the rates in the near future.

#### 8.12. The Invisible Factor

Numerous Aboriginal community members who expressed an interest in participating in this study were not a part of this study. Reasons for these individuals to not participate often resulted from this group living in the margins of society, being “invisible” (Hampton, McKay-McNabb, Jeffery & McWaters, 2007). Most importantly, APHAs and APAAs are not historically identified in psychological literature (Prentice et al., 2000; Anderson, 2000). These potential participants likely would have had much to share if they had participated. These participants’ life experiences were not shared and ultimately their stories have been missed in this study.

#### 8.13. Interventions

Quality of life (QOL) has been associated with longer survival time for individuals with chronic diseases, including HIV/AIDS. Friedland, Renwick and Mccoll (1996) suggest that as survival periods from the time of a HIV-positive diagnosis continues to increase there should be efforts to gain a better understanding about strategies to facilitate adjustment and well-being, specifically in the area of QOL. They

suggest that potential interventions may be influenced by social support and coping styles. Previous researchers suggest that social support has resulted in positive health outcomes with individuals who have been diagnosed with HIV/AIDS (Kalichman, DiMarco, Austin, Luke & DiFonzo, 2003; Brashers, Neidig & Goldsmith, 2004; Bahrat, 1996). Freidland and colleagues (1996) findings suggest social support is important and the participants in their study highlighted the importance of emotional support received and how this had direct impacts on their quality of life. Further studies are required to gain better insight about the potential of social support and how coping may influence QOL with individuals who are diagnosed with HIV/AIDS.

Treatment and interventions have the potential to facilitate for healing by utilizing the model of transformation. It is my hope that this model will be adapted and utilized for healing and developing psychological interventions for HIV/AIDS. This model identified that an individual who is diagnosed with HIV or has a loved one diagnosed with HIV navigate through stages of transformation. This model has the potential to be adapted and utilized for other chronic illness within Aboriginal communities. Researchers have identified that a community psychology approach within Aboriginal communities is based on distinctions between traditional clinical services and community mental health approaches (Gone & Alcántara, 2007). For example, they suggest that instead of extended psychotherapy, the strategy of mental health provision should be brief consultations and crisis interventions with groups of individuals. The model identified in this study has the potential to assist direction of community mental health for HIV/AIDS and Aboriginal communities.

#### 8.14. Implications

It is my hope that the results of this research project will benefit for Aboriginal community members in Canada, mental health practitioners, service providers and community agencies that provide support to APHAs and APAAAs. The role of an individual's identity when they are diagnosed with HIV/AIDS or have a loved one who is diagnosed with HIV/AIDS transforms as they navigate through emotional feelings and experiences, with movement towards embracing the transformation to a new identity. Ultimately, gaining a better understating of the individuals experience is particularly important when providing supports. However, care must be taken when providing support, as numerous participants identified challenges with developing trust with service providers, due to the historical traumas they had experienced. For the APHA and APAA participants, exploring ways that may assist in their healing involved psychological and cultural aspects. Trust was identified by the participants as being important when accessing services or supports. In a therapeutic relationship, respect, trust and rapport building is crucial to the healing process. In the transformation of identity, the essence of trust is a factor that ultimately assists in the psychological and cultural healing of an individual who is diagnosed with HIV/AIDS or supports a loved one.

For APHAs, support was identified as accessing another APHA or an ASO/AASO. An APAA may not choose to access services or supports and may carry the burden of secrecy for years. Understanding that both experiences are unique, the common aspect was the level of trust and understanding that they were seeking. For service providers and support agencies, having access to referrals for cultural and spiritual supports will be helpful to those APHAs and APAAAs who are working towards their healing journeys.

APHAs and APAAs are made up of diverse Aboriginal population across Canada. Within this diversity, there is much to learn and there is not one way in this experience, there are many. As indicated in previous sections, the “invisible” emerged as a missing piece, where there is a group of Aboriginal individuals who did not participate in this study. They are the invisible ones, who likely have much to add by sharing their stories.

#### 8.15. Strengths

Strength of a qualitative approach is that it enhances the possibility of a deeper understanding of the complexity and importance of context in dealing with issues related to HIV/AIDS and Aboriginal communities. In this study, Aboriginal community members in Canada who had experienced HIV/AIDS were heard in a way that acknowledged their wisdom, strength, and valued their life experiences. The nature of the qualitative approach to research encourages a sensitivity and respectful response to any vulnerability that the participant may experience. Ultimately, this resulted in a depth of sharing their life stories that has assisted me in gaining a better understanding about HIV/AIDS within the Aboriginal Canadian population.

#### 8.16. Contributions

Considering the limited amount of literature with respect to life experiences of APHAs and APAAs, this study makes several important contributions. First, the present study appears to be the only study to date that has investigated the life experiences of Aboriginal community members in Canada. Most of the literature about Aboriginal people and HIV/AIDS focuses attention on the negative implications of this chronic disease instead of attending to the strengths of the individuals who continue to live their

lives and to continue their journeys. As a result, there is a need for future strengths based research to be conducted within the Aboriginal communities in Canada.

#### 8.17. Limitations

As with all qualitative studies, the sample size limits the generalizability of research findings to a broader community. Although it is not generalizable, the model that emerged from this study could be used with other chronic diseases, such as diabetes. It is my hope that the model of *Psychological and Cultural Healing: Transformation of Identity* that emerged from the stories will be strengthened through future research. The process of healing and identity described by many of the participants in this study warrants further investigation. It was useful to investigate APHAs and APAAs who were at different stages of their journey of transformation, some being at the first few stages, others having come full circle in their experiences. Ideally, a future study of APHAs and APAAs in Canada would certainly benefit the paucity of literature that currently exists regarding life experiences of Aboriginal communities and HIV/AIDS.

Another limitation in my research is the sampling methods. The APHAs and APAAs who came forward to be interviewed may represent a biased sample (representative sampling). The APHA participants who participated in this research have healed and grown over time to speak openly about their illness and may not represent those who have not lived with the illness long enough to feel comfortable speaking out about their experience, or who choose to never discuss it. The APAA participants rarely spoke about their loved ones illness with anyone. I feel honored that there were six brave Aboriginal community members who trusted enough to share their experiences of being APAAs in hopes of assisting others. Hopefully, their experiences will assist in future

healing and better understanding of HIV/AIDS within the many Aboriginal communities in Canada. Most importantly, there are those individuals who remain “invisible” who did not participate in this research due to psychosocial and individual stressors.

Finally, one of the most significant limitations in this study was the ability to gather stories from APHAs that are not on their healing journey. In Saskatchewan, where I am geographically located, I had thought I would be able to engage numerous APHAs within Saskatchewan, due to this province having one of the highest reported rates in Canada. Specifically, in 2009, 94 new HIV/AIDS cases were reported, with a large number of these being young Aboriginal women (Opondo, 2011). Aboriginal people in Saskatchewan continue to be disproportionality represented in new HIV diagnosis cases. Specifically, in 2010 there were 125 new cases of HIV that self-identified as being Aboriginal compared to 39 new HIV cases being non-Aboriginal (Saskatchewan Ministry of Health, 2011). It is imperative that more emphasis be focused on this group people, as the cases continue to increase, as well as those individual also increase but remain “invisible”.

#### 8.18. Future Directions

Given the dearth of literature investigating Aboriginal community member’s life experiences of HIV/AIDS in Canada, future directions for research are abundant. First, further qualitative studies of life experiences of Aboriginal community members in Canada are required. These studies should make every attempt to include individuals who are “invisible” to participate, those whose voices are not being heard. It was observed in this study that there are potential participants that would have liked to participate, but life

circumstances, psychosocial and individual issues prevented them for sharing their experiences.

The findings of this study identified that APHAs and APAAAs are at different places in their journey of transformation with HIV/AIDS. Further investigations should be conducted to assist in understanding Aboriginal community member's life experiences and how supports and services, psychological interventions and therapy may assist them.

Further research examining the model of *Cultural and Psychological Healing: Transformation of Identity* may be beneficial to other chronic diseases. The model has the potential to be utilized to gain a better understating of other chronic diseases, by following the stages of healing on the journey to transformation.

#### 8.19. Personal Reflection

Ultimately, I have come to a point in my life where I have realized that this journey I have had the privilege to be a part of happened in my life for a reason. I have been raised and mentored to believe in circumstances, life experiences and things happening for reasons. This is one of the teachings I have come to live my life by. In the past, I conducted this research because I as an APAA had not been able to locate supports or services to assist with the emotional turmoil that resulted from having a sister diagnosed with HIV/AIDS. Ultimately, over time, this journey emerged as being more for our Aboriginal community members than for myself.

I come from a matriarchal lineage of healers and my purpose in a spiritual sense is to be a healer. I have dedicated my life to emotional, spiritual, mental and physical aspects of cultural healing and holistic healing methods. It is important for the work that I

do in the future to continue to build on this dissertation, as I know there is still much to learn and share.

In 2005 I was in a routine medical procedure that gave me a brief glimpse into the emotional turmoil that accompanies an HIV/AIDS diagnosis. I attended a pre-procedure appointment with my specialist, to conduct a colonoscopy, as my family has a history of colon cancer. At this time, an intern came in and asked me a number of what I had thought were routine questions. He asked, I answered. During this time, I was beginning to become impatient, as he was asking questions that I had no answers to, such as T-4 counts, etc. He left the room and when he returned, he had three other interns and the specialist by his side. It was at this time, that the Dr. said “Kim, we cannot continue with your procedure tomorrow, as you are HIV positive and the devices will be required to be sterilized immediately after your procedure.” I leaped off the table, white paper sheet and all, to ask him to repeat what he just said. He repeated himself and I immediately followed his response and asked him, “Are you telling me I am HIV positive like this? Without me having a support person? Where is infectious diseases? Where is a social worker?” The Dr. looked very surprised when I started to shoot off questions. He and the three interns excused themselves. As soon as they left the room, I got dressed. I did not wait for them to return. I was in a haze of emotional turmoil. I immediately called my family doctor and explained what I had just experienced in my appointment. My family doctor was also surprised, if not shocked. I requested he track down all of my medical records, as I wanted to meet with him that afternoon. He agreed and I met with him. It took more than six weeks to track down a medical record mistake from another specialist that had resulted in someone adding to my file that I was HIV positive. At the time, I was



overwhelmed with the physical, emotional, mental and spiritual experience of learning that I was HIV positive. Over a span of six months I was under the impression that I was HIV positive. Ultimately, this meant that my husband must also be HIV positive. We eventually learned together, through series of tests and exams, that neither of us was HIV positive. I believe at this time in my life, I was already fully invested in working with Aboriginal communities and HIV/AIDS. However, once this lesson was presented to me, I embraced it, as always, with the ‘things happen for reason’ and know in my heart and soul this experience assisted me in a deeper understanding and resulted in more passion towards this work. Hiy Hiy Creator – I am blessed with this lesson and will continue on in my journey with open heart and mind – to do all that I can to within our Aboriginal communities in Canada and fight this virus – ekosi!

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## **APPENDICES**

Appendix A  
University of Regina Ethics Board Approval



UNIVERSITY OF  
REGINA

OFFICE OF RESEARCH SERVICES

MEMORANDUM

DATE: November 10, 2009

TO: Kim McKay-McNabb  
78 Scrivener Crescent  
Regina, SK S4N 4V7

FROM: Dr. Bruce Plouffe  
Chair, Research Ethics Board

Re: **Aboriginal Communities and HIV/AIDS: A Qualitative Inquiry – The Voices Must be Heard (File # 21S0910)**

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Please be advised that the University of Regina Research Ethics Board has reviewed your proposal and found it to be:

1. APPROVED AS SUBMITTED. Only applicants with this designation have ethical approval to proceed with their research as described in their applications. For research lasting more than one year (Section 1F). **ETHICAL APPROVAL MUST BE RENEWED BY SUBMITTING A BRIEF STATUS REPORT EVERY TWELVE MONTHS.** Approval will be revoked unless a satisfactory status report is received. Any substantive changes in methodology or instrumentation must also be approved prior to their implementation.
2. ACCEPTABLE SUBJECT TO MINOR CHANGES AND PRECAUTIONS (SEE ATTACHED). Changes must be submitted to the REB and approved prior to beginning research. Please submit a supplementary memo addressing the concerns to the Chair of the REB.\*\* Do not submit a new application. Once changes are deemed acceptable, ethical approval will be granted.
3. ACCEPTABLE SUBJECT TO CHANGES AND PRECAUTIONS (SEE ATTACHED). Changes must be submitted to the REB and approved prior to beginning research. Please submit a supplementary memo addressing the concerns to the Chair of the REB.\*\* Do not submit a new application. Once changes are deemed acceptable, ethical approval will be granted.
4. UNACCEPTABLE AS SUBMITTED. The proposal requires substantial additions or redesign. Please contact the Chair of the REB for advice on how the project proposal might be revised.

  
Dr. Bruce Plouffe

cc: Dr. Mary Hampton – Psychology – Luther

\*\* supplementary memo should be forwarded to the Chair of the Research Ethics Board at the Office of Research Services (Research and Innovation Centre, Room 109) or by e-mail to [research.ethics@uregina.ca](mailto:research.ethics@uregina.ca)

**Appendix B**  
**Participant's Informed Consent Form**  
**Life Experiences of Aboriginal Communities and HIV/AIDS**

You are invited to participate in this research because you are an Aboriginal person who has a personal experience of HIV/AIDS.

**Purpose of Study:** The purpose of this study is to develop an understanding of the life experiences of living with HIV/AIDS from the perspective of Aboriginal Peoples. There is limited research describing Aboriginal Peoples experiences of living with HIV/AIDS. This research will contribute useful information documenting their life experiences that Aboriginal people face when they are living with or affected by HIV/AIDS.

**Requirements:** Participants are invited to voluntarily fill out a background information form and participate in an interview to discuss your life experiences with HIV/AIDS. The interview length is flexible, but it is estimated that it will last approximately one hour and a half. It will be tape recorded to ensure accurate representation of your words. You will then be required at a later time to review the written transcript to verify the accuracy of your story and research findings.

**Participants:** The study requires the voluntary participation of people who have experienced HIV/AIDS or are supporting an Aboriginal individual who has been diagnosed with HIV/AIDS.

**Potential Benefits:** There are no potential benefits to the participants other than the sharing your experience of living with or being affected by HIV/AIDS along with gaining knowledge which you may acquire about the research process.

**Potential Risk and Discomfort:** Participants should not experience any discomfort or risk in completing the background information form or participating in the interview. If any of the participants experience distress because of the content of the interview a registered psychologist will be available for consulting. The AIDS service organizations that I plan to recruit from have counsellors available on site for psychologist and qualified medical support of clients.

**Confidentiality of the Data:** Your name will not be associated in any way with your data. Your consent form will be stored separately from the data. My supervisor and I will have access to individual results of the study, only a summary of the results.

**Withdrawal From The Study:** Participation is voluntary. If at any time during the research you decide for any reason you do not wish to participate you are free to withdraw from the study. Your decision whether or not to participate will not affect your present or future relationship with the University of Regina or from the AIDS service organization that you attend.

**Questions:** If you have any questions before, during or after the interview, feel free to contact the researcher or the project adviser.

This project will be submitted to the Research Ethics Board, University of Regina. If research subjects have any questions or concerns about their rights or treatments as subjects, they may contact the Chair of the Research Ethics Board at 585-4775 or by e-mail: [research.ethics@uregina.ca](mailto:research.ethics@uregina.ca).

YOUR PARTICIPATION IS VOLUNTARY. YOUR SIGNATURE INDICATES THAT YOU HAVE DECIDED TO PARTICIPATE IN THIS STUDY AFTER READING THE INFORMATION PROVIDED. YOU WILL BE GIVEN A COPY OF THIS CONSENT FORM FOR YOUR OWN RECORD. THE INVESTIGATOR WILL ALSO KEEP A SIGNED COPY ON FILE.

PARTICIPANT'S SIGNATURE \_\_\_\_\_ DATE \_\_\_\_\_  
RESEARCHER SIGNATURE \_\_\_\_\_ DATE \_\_\_\_\_

Researcher: Kim McKay-McNabb, MA. University of Regina, Department of Psychology, 306-585-4045 e-mail: [Kim.McNabb@uregina.ca](mailto:Kim.McNabb@uregina.ca)





## **Appendix D Email Recruitment**

Dear \_\_\_\_\_,

This fall I will begin a study with Aboriginal People's who have been effected by (been diagnosed with) or affected by (relative has been diagnosed with) HIV/AIDS. The study is titled "*Aboriginal communities and HIV/AIDS, A Qualitative inquiry: The voices must be heard*". The purpose of this research is to develop a better understanding of how HIV/AIDS is changing the health landscape within Aboriginal communities. My interest in this area developed through my own personal experience when I was affected by HIV/AIDS. My eldest sister was diagnosed with HIV/AIDS in the late eighties. It is in her memory that I continue to dedicate part of my life's work to the area of HIV/AIDS and Aboriginal People's.

I would like to extend an invitation to your agency to assist in this important research study with Aboriginal People's. It is my hope that you may be able to help with recruiting Aboriginal community members (both urban and an on-reserve) to participate in interviews for this study. The criteria for participating are

- (1) You are an Aboriginal person who has a HIV positive diagnosis/AIDs status
- (2) You are an Aboriginal person who has a family member who has been Diagnosed with HIV/AIDS
- (3) You are an Aboriginal person who over the age of 18
- (4) You self-identify as having an Aboriginal identity.

If you agree to help with this recruitment, I would ask that you provide interview packages to Aboriginal community members who may fit the research criteria. Included in the package will be information about the research project, an overview of the interview focus, criteria for participation, and contact information if the potential participant is interested in being interviewed or is interested in accessing further information. Aboriginal People's who are interested will have the option of making contact through email or telephone.

The interviews will be open ended either in person or by telephone. I will conduct approximately 25 qualitative open-ended interviews with Aboriginal community members from across Canada who have been effected by (been diagnosed with) or affected by (relative has been diagnosed with) HIV/AIDS to gain a better understanding of how HIV/AIDS is changing the health landscape within Aboriginal communities. Grounded theory methodology will be used to analyze the interview data. I do look forward to developing a relationship to assist in gaining a better understanding of HIV/AIDS and Aboriginal Peoples. I will be in touch in the next month to discuss my research study.

With respect,

Kim McKay-McNabb, M.A.

## **Appendix E**

### **Description of Study**

**Title of study:** *Aboriginal communities and HIV/AIDS, A Qualitative inquiry: The voices must be heard.*

**Researcher:** Kim McKay-McNabb, M.A.

**Background of study:** The purpose of the proposed research is to generate a culturally relevant theory describing experiences of Aboriginal community members affected HIV/AIDS. This theory can guide psychological services for Aboriginal communities as they cope with the effects of HIV/AIDS. Presently, there is a lack of literature that includes Aboriginal voices sharing their life experiences.

The focus of this research is on Aboriginal communities and I will recruit Aboriginal Peoples who reside in both urban and reserve settings, but who self-identify as Aboriginal, to participate.

History has not accurately portrayed Aboriginal Peoples' health and lifestyle. The implications of this inaccurate description of Aboriginal Peoples' health are one of the reasons for this study to assist to portray an accurate description of Aboriginal Peoples' health and wellbeing. I will be collecting data with Aboriginal participants to construct a theory that more accurately describes not only present-day health of Aboriginal communities who are affected by HIV/AIDS, but hopefully develop an understanding of traditional values and lifestyle that can be communicated orally through qualitative interviews.

**Research** The purpose the proposed research is to develop a theory grounded in the experience of Aboriginal community members in Canada that describes ways in which they have been affected by HIV/AIDS. This theory will incorporate the effects of colonization within Aboriginal communities; although historical, effects of colonization have been linked by researchers to many health challenges confronting Aboriginal communities today. This thesis will review research evidence that suggests the higher prevalence and incidence of HIV/AIDS in Aboriginal communities has roots in historical colonization.

**Participants:** I hope to interview fifteen Aboriginal community members who have been diagnosed with HIV/AIDS and ten Aboriginal community members whose family members have been diagnosed with HIV/AIDS (i.e., "affected by"). In total, 25 Aboriginal individuals living in Canada who have been affected by HIV/AIDS will be interviewed. Participants will be recruited from AIDS service organization in Canada. Criteria for participating in the study will be: (1) HIV positive diagnosis/AIDS status; (2) a family member have been diagnosed with HIV/AIDS; (3) over the age of 18; (4) of self-identified Aboriginal identity.

**Study Design:** Interviews will be open ended either in person or by telephone. I will conduct approximately 25 qualitative open-ended interviews with Aboriginal community

members from across Canada who have been effected by (been diagnosed with) or affected by (relative has been diagnosed with) HIV/AIDS. The research questions guiding this study are: 1) Can you describe your experience of living with or being affected by HIV/AIDS? 2.) How did you learn that you were HIV positive or how did the person whom you are affected by learn they were HIV positive? 3.) Do you access cultural and spiritual supports for coping with HIV/AIDS a part of the process? 4.) Does stigma and discrimination affect your journey with HIV/AIDS? 5.) Does living on reserve or in an urban setting affect how you cope with HIV/AIDS? 6.) Does the holistic health model, of spiritual, emotional, physical and mental aspects assist you or the person affected by HIV/AIDS with coping with HIV/AIDS?

**Appendix F  
Background Information**

*All information that you share on this sheet will be kept confidential.*

Today's Date: \_\_\_\_\_

Date of Birth: \_\_\_\_\_

Marital Status: \_\_\_\_\_ Single \_\_\_\_\_ Married \_\_\_\_\_ Divorced  
\_\_\_\_\_ Common-Law \_\_\_\_\_ Other

Children: \_\_\_\_\_ No \_\_\_\_\_ Yes: Ages of Children \_\_\_\_\_

Aboriginal is defined as a person who is First Nations status, First Nations Non-status, Métis or Inuit.

Do you identify as being Aboriginal? \_\_\_\_\_

If yes, please self identify as:

First Nations status \_\_\_\_\_

First Nations non-status \_\_\_\_\_

Métis \_\_\_\_\_

Inuit \_\_\_\_\_

Do you belong to a First Nation? \_\_\_\_\_ If yes, which one? \_\_\_\_\_

Do you belong to a local? \_\_\_\_\_ If yes, which one? \_\_\_\_\_

Highest Level of Education Completed \_\_\_\_\_

How long have you been affected / affected by HIV/AIDS? \_\_\_\_\_

Have you experienced a pregnancy while living with HIV/AIDS? \_\_\_\_\_

Do you currently receive service from an AIDS service organization?

Yes \_\_\_\_\_ No \_\_\_\_\_

If yes, where? \_\_\_\_\_

In your opinion, what is the most important services that you would like to see developed to assist with gaining a better understanding of HIV/AIDS.

## Appendix G

### Guideline of Open-ended Qualitative Interview

1. I am interested in your experience with HIV/AIDS. Can you please talk about your experience of HIV/AIDS or Tell me the story of your experience with HIV/AIDS?

Probes:

- Can you describe the feelings you experienced when you first learned about being positive?
- Can you share with me who you first disclosed your positive status with?

2. I am also interested in how you feel you, as an Aboriginal person, have experienced HIV/AIDS. Can you tell me if you experience support from your First Nations community?

Probes:

- Can you tell me about the support you receive from your immediate family/extended family?
- Can you tell me if there is someone you can speak with about your illness?

3. I am hoping to develop guidelines for providers of services to Aboriginal communities who are suffering with HIV/AIDS. I wonder if you have any advice.

Probes:

- Would you prefer speaking with an Aboriginal front line service provider for support and services?
- Would you like to meet with other people who are affected with HIV/AIDS?
- Do you feel like you know how to cope with your illness?
- What would you like to see in the future for other Aboriginal communities who will experience HIV/AIDS?

## **Appendix H**

### **Referral Sources**

1. Healing Our Nations (Dartmouth, Nova Scotia)  
  
(902) 492-4255  
  
1-800-565-4255  
  
[www.hon93.ca](http://www.hon93.ca) or [ea@accesswave.ca](mailto:ea@accesswave.ca)
  
2. Canadian AIDS Treatment Information Exchange (Toronto, Ontario)  
  
1-800-263-1638  
  
[www.catie.ca](http://www.catie.ca) or [questions@catie.ca](mailto:questions@catie.ca)
  
3. Canadian Aboriginal AIDS Network (Ottawa, Ontario)  
  
(604) 266-7616  
  
1-888-285-2226  
  
[www.caan.ca](http://www.caan.ca) or
  
4. The Ontario HIV Treatment Network (Ottawa, Ontario)  
  
(416) 642-6486  
  
1-877-743-6486  
  
[www.ohtn.on.ca](http://www.ohtn.on.ca) or [info@ohtn.on.ca](mailto:info@ohtn.on.ca)
  
5. Nine Circles Community Health Centre (Winnipeg, Manitoba)  
  
(204) 940-6000  
  
1-888-305-8647  
  
[www.ninecircles.ca](http://www.ninecircles.ca)
  
6. All Nations Hope AIDS Network (Regina, Saskatchewan),  
  
(306) 924-8424

1-877-210-7622

[www.allnationshope.ca](http://www.allnationshope.ca) or [allnationshope@sasktel.net](mailto:allnationshope@sasktel.net)

7. Saskatchewan, AIDS Program South Saskatchewan (Regina, Saskatchewan)

(306) 924-8420

1-877-210-7622

[www.aidsprogramsouthsask.ca](http://www.aidsprogramsouthsask.ca) or [aidsprograms@sasktel.net](mailto:aidsprograms@sasktel.net)

8. Healing Our Spirit (Vancouver, British Columbia)

(604) 879-8884

1-866-745-8884

[www.healingourspirit.org](http://www.healingourspirit.org) or [info@healingourspirit.org](mailto:info@healingourspirit.org)



