

HIV Prevention from Indigenous Youth Perspectives

by

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ABSTRACT

This qualitative study of six Indigenous youth HIV prevention peer educators is presented to help understand how Indigenous youth perceive HIV/AIDS education. The research used a semi-structured questionnaire as a guide to conducting in depth individual interviews. The research followed decolonizing methodologies to explore the views of peer educators about the HIV/AIDS education they delivered, and the issues around perceptions of infection and risk. It examines the youth's views on peer education, the importance of cultural revitalization in relation to health education and how peer education can be most effective. This study has included examples of programs with marginalized communities in several parts of the world and compared them with Indigenous experiences in Canada, in order to develop an understanding and recommendations of the most effective approaches in Indigenous youth health interventions. There have been very few research studies on Indigenous youth involvement in STD interventions. Indigenous youth have only been marginally included in the design of most of the social programming they receive, even though they have the unique knowledge, skills, language and cultural perspective necessary to reach their peers. HIV infection is on the rise with Indigenous youth because of historical and ongoing socio-economic and political inequities. Therefore, it is crucial that young Indigenous people be welcomed as integral participants in the strategies for improving Indigenous health.

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LOGO

The logo on the cover was designed for me by my cousin, Una Ann. Una Ann is a Tahltan artist who designs clothing, accessories, crafts, murals, jewelry, regalia, and more, in both contemporary and traditional styles. She also works full time as an Aboriginal Support Worker for the Langley School District.

Part of my family background comes from the Tahltan Nation, which has two clans, Crow and Wolf. My family is from the Crow clan. Clan systems are very important for many Indigenous Nations. Clans are like an extension of one's family, and are a significant part of one's identity. Clans represent roles and responsibilities, which are particularly noticeable today during major events, such as ceremonies and funerals. Clans were also important in political decision making, but had more influence in this respect prior to the imposition of the *Indian Act*.

The logo is an image of both Tahltan clans and the AIDS ribbon. This combination represents the Indigenous connection to HIV/AIDS and recognition of Indigenous forms of healing. The clan images illustrate the significance of knowing and being connected to one's identity in ensuring healthy lifestyle choices. The ribbon represents solidarity and unites all peoples in the fight against HIV/AIDS.

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ACKNOWLEDGEMENTS

My research project is a result of the impact that was made on me from my work at Healing Our Spirit HIV/AIDS Society (HOS) in Vancouver. Learning about the issues surrounding HIV/AIDS and how every individual is affected in some way by this virus had a lasting impression on me. The Indigenous youth peer educators have inspired me and reached me deep in my heart. They are leaders and role-models, and their contribution to social programs helps to create ways of learning that are comprehensive and vital. Nadina, Reno, Thomas, Cheyenne, Sueann, Tristan, Tommy and all the youth who contributed to Sunfire Aboriginal Youth Services at HOS have motivated me to do this work.

My interest and support of peer education began however prior to my work at HOS. Working in Lithuania, Cyprus and Canada with the United World College Short Courses, from 1999 to 2001, allowed me to experience the dynamic abilities of young people in learning, sharing and teaching. During this time I was also coordinating an Anti-Racism Project in East Vancouver. That was when I met Santana, Heather, Chuckie and Leonard. Among the many things they taught me was the importance of having a sense of humour in the face of adversity. Through peer education they taught hundreds of children, their peers and adults about the racism they experience. They continue to captivate me with their wit and their vigor.

I would like to acknowledge the Indigenous Governance program for the exceptional education they provided me in the first two years of my degree. I would

like to thank my thesis supervisor, Dr. Ted Riecken, for his patience and ongoing support of me, and his support of the many issues of concern to youth. I would like to express my gratitude to my committee member Dr. David Blades for his time and encouragement, and Dr. Lara Lauzon for joining my committee at the last minute.

My friends and family have been extremely supportive and generous throughout my research. Jasmine Osman and Michael Norman kindly spent many hours assisting me with the difficult job of transcribing, and Jessica Cook printed and delivered the many copies of my thesis drafts to my Professor's offices in Victoria. I am so grateful to each of them for their help. My cousin Una Ann designed the logo for me, and John Crosby transferred it into a digital file after several hours on Photoshop following requested changes from me. My dad, Heino Leis, was a role model to me for his love of academia and his perseverance in completing his MBA. His encouragement and appreciation for the experience of graduate school has provided me with so much support and validation. I thank my parents for their financial assistance throughout my studies, and my siblings, cousins, aunts and uncles for their ongoing encouragement. Everyone has been so patient and understanding with me throughout this process.

Finally I would like to recognize Jason Peacemaker and David Lee for teaching me a new kind of compassion and strength.

When you change the way you look at things, the things you look at change.

Dr. Wayne Dyer, as shared with me by Jason Peacemaker

DEDICATIONS

To Salme, Nelson and Natasha. For all the challenges we faced in our youth and everything that keeps us strong today.

To Heather Mack, Chuckie Mack, and Leonard Ambrose. For talking about issues that challenge the status quo and for standing up for what you believe.¹

To all of the people who have passed on as a result of AIDS, this work is done in your name.

¹ I have permission from each of the three youth to mention their full names. They were not interviewees for this research.

TERMINOLOGY AND ACRONYMS

In contemporary health literature and academic writing “**Aboriginal**” seems to be the most commonly used term, as it is considered inclusive of status, non-status, Métis and Inuit peoples. It is a term defined in the Constitution Act of 1982, and it actually does *not* include non-status Indigenous peoples, only Métis, First Nations/status-Indian, and Inuit peoples (Assembly of First Nations, 2005). I have therefore chosen to use the term “**Indigenous**” to refer to the original inhabitants of Canada. The term “Aboriginal” is used in this paper when referring to specific organization’s names. These two terms, along with “Native” are used interchangeably by interviewees. The term Indian is only used in the wording of government legislation, in the names of political organizations and in citations.

The term “**youth**” is used to refer to young people under the age of 30. This is the legal age limit that the federal government uses to determine who is a “youth” for purposes of project funding, and denotes the maximum age of staff who can be employed in these projects. This legal definition is reflected in the ages of interview participants. They range from between 18 to 27.

STD (Sexually Transmitted Disease) versus **STI** (Sexually Transmitted / Transmissible Infection): “The term ‘infection’ more accurately describes conditions where sexual partners may not have symptoms and may not be aware that they have an infection, and because many of these infections are actually curable. The term

infection carries less of a social stigma than the term ‘disease’.” (Brown University Health Education, 2004, STI vs. STD section).

HIV: **H**uman (only affects humans) **I**mmunodeficiency (attacks the body’s defense system opening it to disease and infection) **V**irus (HIV is a germ that causes AIDS). HIV slowly breaks down the body's immune system, making it easier to get a variety of illnesses, known as "opportunistic infections" (YouthCO AIDS Society [YouthCO], 2005, Transmission Equation section; AIDS Vancouver, 2005, The Basics section).

AIDS: **A**cquired (AIDS is something a person gets because of an HIV infection) **I**mmuno (refers to the body’s natural defense system against disease and infection) **D**eficiency (the immune system isn’t able to fight off disease and infection) **S**yndrome (a set of diseases that takes advantage of the body’s weakened immune system). AIDS is understood to be caused by prolonged infection with HIV (YouthCO, 2005, Transmission Equation section; AIDS Vancouver, 2005, The Basics section).

PHA: Person Living with HIV or AIDS.

APHA: Aboriginal Person Living with HIV or AIDS.

ASO: AIDS Service Organization

HIV 101: This refers to teaching the basics about HIV/AIDS. HIV 101 usually includes information on HIV infection (contraction), testing, transmission, stages of the virus, prevention, and a condom demonstration. Many HIV 101 youth presentations are taught with scenarios, role-plays, direct instruction and examples.

HOS: Healing Our Spirit BC Aboriginal HIV/AIDS Society

Sunfire: Sunfire Aboriginal Youth Services, an HIV and Hepatitis C prevention organization that was under the umbrella of HOS.

YouthCO: Youth Community Outreach AIDS Society. A mainstream (non-Indigenous) HIV and Hepatitis C prevention organization.

CHAPTER ONE - INTRODUCTION

A DAY IN THE LIFE OF A PEER EDUCATOR

Nattali² is a volunteer youth peer educator for Raven Tails HIV/AIDS Youth Cares Society. Nattali is 24 years old and from the Tervislik Nation and now resides in Victoria.

Raven Tails is an Indigenous youth HIV/AIDS peer education organization that serves communities throughout BC. Raven Tails employs three staff, one Coordinator, one Outreach Worker, and one Educator/Liaison Worker, all under the age of 30.

Raven Tails, like all Indigenous youth organizations, is funded by the Indigenous Youth Urban Programs Fund. Raven Tails is directed by a Youth Advisory Committee (YAC), which Nattali has sat on for two years. Most of the youth who sit on this committee take part in delivering the peer education workshops and also help out with other events that Raven Tails organizes.

The YAC meet once a month at the Raven Tails office for meetings organized by the staff. Members receive \$10 and a bus ticket for attending each meeting, and members who are single parents also receive money for childcare. If the youth miss three meetings the committee discusses their membership and the reasons for missing meetings, and decides whether they can continue to be a part of YAC.

Activities they organize include the powwow night at the Friendship Centre one night per month, a youth dinner one night per month, and different self-esteem building or awareness events for members of the committee and youth they serve through the Outreach Worker. These events include hair and makeup for girls, sports activities, health promoting music shows, movie nights, etc.

² The names of all of the individuals, organizations and communities in this story are pseudonyms chosen by the researcher.

The Outreach Worker from Raven Tails meets with Indigenous youth on the street and at community events and gives them condoms, HIV information, buys them food, and spends time talking with them while “hanging out” in places where the youth are comfortable. This is usually in a park, street corner or youth centre. Sometimes Nattali and other members of YAC join the Outreach Worker in doing this.

Nattali started volunteering with Raven Tails helping to organize events and take part in meetings. She, along with other YAC members, participates with Raven Tails about two to four days per month, attending the YAC meetings and helping out at different events.

Initially, Nattali was not comfortable with the role of peer educator. However, with appropriate training and ample experience sitting on YAC, she finally felt ready to deliver a workshop. Presentations were conducted together with other YAC members at various places such as high school alternative Indigenous programs for Grades 8-10 students. She usually presented with three other YAC members and the Raven Tails Educator.

Nattali would begin the workshops by introducing herself and her group to the youth in the audience. Her group would immediately put their audience at ease with their laughter and laid back attitudes. The discussion would begin with what is called “HIV 101,” where they use a story of a youth at a powwow who meets another youth that she is attracted to. As the story continues, the youth finds out that from that one sexual encounter after the powwow she became HIV positive. How she continues to deal with this challenge is chronicled through the rest of the story.

The presentations include a condom demonstration, which usually always gets the audience laughing. The peer educators then talk about health according to the Medicine Wheel, and how this applies to them as Indigenous youth today. For the final activity of the workshop, each participant makes themselves a medicine pouch which holds a condom inside. The peer educators talk about the relevance of the pouch, and how condoms are a contemporary form of medicine and protection. When the workshops finish, Nattali and the rest of the group answer any questions the participants have.

Nattali has become very comfortable delivering peer education workshops and enjoys the time she spends with the youth. She presents once every one or two months, as the youth peer educators usually rotate. Nattali feels that participating at Raven Tails has helped her build her confidence in relationships outside of the work relationship, because she is empowered with knowledge. She also feels that she is a role model because other youth listen to what she has to say. This encourages her to continue to be a role model in other aspects of her life and make choices for herself that can teach her peers. She is looking forward to the possibility of becoming a staff member at Raven Tails, or starting her own youth organization.

The story above illustrates many of the events that occur in a day of an Indigenous youth HIV prevention peer educator. My experience working at Sunfire Aboriginal Youth Services involved many of these aspects. The knowledge I gained from my Sunfire job was so meaningful to me that I chose to conduct my research on HIV prevention.

MY JOURNEY AND VISION

In 2003 I began a job as the coordinator of an Indigenous youth HIV/AIDS prevention project, called Sunfire Aboriginal Youth Services (Sunfire), under the umbrella of Healing Our Spirit BC Aboriginal HIV/AIDS Society (HOS). In this job I learned about the prevalence of HIV/AIDS in Indigenous communities, an issue that is fundamentally interconnected with politics, racism, sexism, education, and colonization... all the issues that had been my previous academic and career focus. In many Indigenous experiences, disruptions of identity were created by political legislation, such as the *Indian Act*, which was implemented in 1876, and which determined Indian status and set the groundwork for residential schooling, among others. These policies were in place for racist and religious reasons, and sexism played a part in that women's roles which were understood as central in many communities were disrespected by government agents. Education for Indigenous peoples was often irrelevant and oppressive. All of these factors, including the political issue of territorial displacement, contributed to low levels of health in Indigenous communities. These factors continue to be realities today and are the areas that Sunfire participated in addressing.

When the funding ran out for the Sunfire project in May 2004, the problems created by the absence of Indigenous youth voices in HIV prevention became even more critical. In 2004 we were the only Indigenous youth HIV prevention organization in BC, and one of the few in Canada. Knowing we were closing down, and that we were one of the first opportunities other AIDS Service Organizations (ASO's) had for learning about Indigenous youth HIV prevention approaches, these ASO's began scrambling for our youth to become involved with them. They hoped to recruit the Sunfire youth and were

asking for our input on their curricula. This made evident the cultural exclusion that mainstream HIV prevention education can be partial to, and the need for Indigenous youth participation. Only one Sunfire youth joined a non-Indigenous ASO however, and I believe this has to do with the importance of relationship connections as I discuss on page 47 in Chapter Three. From my experience there are very few to no Indigenous staff or youth at mainstream ASO's and when there are there is usually only one position available for engaging specifically with the Indigenous community. The one position is not always filled by an Indigenous person. The ASO's that I have been speaking of do give presentations on reserve and now no longer have access to an Indigenous youth HIV organization in BC for input.

Indigenous youth have a lot to say about their health and the health of their communities. Their voices, however, are not being heard. They are the ones who are experiencing a high increase in the spread of HIV (as is discussed on page 9), but not enough is being done about it. More Indigenous programs are needed to target youth on reserves and urban Indigenous youth. The mainstream ASO's which I have encountered want to be inclusive of Indigenous health concerns, and there are small ways in which they are attempting to do that. While at Sunfire I worked on a poster campaign with YouthCO, and the Canadian AIDS Society also encourages Indigenous inclusiveness. In order to serve Indigenous communities thoroughly and effectively, Indigenous programs need to be run and delivered by a majority Indigenous staff. As I discuss in Chapter Two about peer relations (see pages 23), members of the same groups often have the unique ability to communicate to their peers with similar language, perspectives and experiences. Mainstream ASO's simply having one or two Indigenous participants is not enough to

make an impact on Indigenous health concerns. In 2005 I was told by a former non-Indigenous ASO volunteer that one of the lead staff at the non-Indigenous ASO had commented within their office that she didn't understand why there had to be a separate organization for Indigenous HIV prevention, and that they all should just be one as there was no difference and that prevention is prevention. This thesis presents my argument that Indigenous HIV prevention needs are different and deeper than what mainstream prevention techniques provide. This includes first and foremost an inclusion of culture and identity to Indigenous health protection.

Given the observations and impressions that I formed during my work at Sunfire, it seemed that my research would best be served in helping to fill the gap of Indigenous youth voice and cultural relevancy in HIV prevention education. It is my hope that in forming research-based recommendations promoting inclusive HIV prevention interventions, that ASO's and educators will use these suggestions in order to decrease the numbers of newly infected Indigenous youth.

PERSONAL CONNECTEDNESS

I was raised for much of my life by my "step" mother who is from the Tahltan Nation. Most of my family whom I know and am close with are Tahltan. Tahltan Indigenous worldview, combined with my father's Estonian heritage and my biological mother's Mediterranean background (Catalonian, Italian and French) frames much of how I see and understand the world. I've chosen my research to work specifically with Indigenous communities and youth, two of the most marginalized groups in Canada, and on infectious diseases.

On March 4, 2006 I was attending the University of Victoria's Distinguished Speaker Series. The speaker was Dr. James Orbinski, the former president of Doctors Without Borders. His talk was on "Global Health" and he spoke about infectious and preventable diseases around the world. When people have worked on infectious diseases in developing countries they often talk about HIV/AIDS and tuberculosis (TB) hand in hand. Dr. Orbinski was discussing war-torn countries, poverty and oppression in relation to AIDS and TB. It was then that it finally hit me why I had become so impassioned working in the field of prevention of infectious diseases and social justice. As I sat in this lecture restraining myself from breaking into tears I was struck with the realization of the impact that infectious disease has played in my life... and the role that it continues to play. "Oh my god it's tuberculosis!!" I gasped to myself. Tuberculosis and the trauma caused by war have affected me my whole life.

My father came to Canada from Estonia as a displaced person during the Second World War. Not only was he plagued by the experience of war and his father's survival of two near executions in German Lager concentration camps, but his young life was also assaulted by tuberculosis. He contracted TB on the crowded boats while escaping Estonia on the way to Germany.

This disease affected my family and me all too personally. My whole life I have seen my father suffer the after-effects of TB. The prevention of the pain and suffering caused by infectious diseases drives me today because of the unbelievable survival skills of my father, and his ability to fight back and surmount the obstacles that continue to impact his health. He is now 63 and becoming increasingly ill due to how TB deteriorated his lungs. I now realize that my father's health and political-cultural history play a

significant role in my personal connectedness to issues of social injustice, health and infectious disease.

Indigenous experiences affect me personally through my family, and youth marginalization is something that has also personally affected me. I have often seen youth, when given the opportunity, thrive at things that many people believed they could not accomplish. This motivated my research because many peer educators, prior to becoming peer leaders, experience adults having little faith in them.

BACKGROUND ON PEER-EDUCATION, HIV/AIDS AND INDIGENOUS REALITIES

Peer education has been found to be a very effective tool in reaching youth in high schools and community settings (Ott, Evans, Halpern-Felsher, Eyre, 2003). Peer outreach commonly addresses youth-at-risk, and is a very important aspect to the overall goal of all forms of prevention education in the Indigenous youth community. Peer outreach (aka peer education) tries to reach at-risk and/or street-entrenched youth. An example of this in the AIDS field is Youth Community Outreach Society's (YouthCO) "speaks," which are workshops that their youth members give to peers in schools and organization around Vancouver. Some well-funded peer education organizations provide drop-in centres for HIV affected, infected and supportive youth, and youth-friendly web sites brochures and zines (youth-driven free magazines). In schools students are supposed to learn about HIV/AIDS in Career and Personal Planning (CAPP) classes from Grades eight through twelve. All of these programs make a contribution and should therefore continue. However, none of these programs are designed to include the experiences of Indigenous youth specifically and that is creating serious problems.

The need for Indigenous youth to educate their peers about high-risk behaviours is imperative. The areas of highest risk and which are among the realities experienced by Indigenous youth include unsafe sex, drug use, and tattooing and piercing that can lead to infection of HIV (and other infectious diseases). “Aboriginal people comprise 16 per cent of those testing newly positive for HIV, while making up only 4 per cent of the B.C. population” (Provincial Health Officer [PHO], 2002, p. 109). Indigenous HIV/AIDS cases in Canada are also much younger than non-Indigenous cases. Out of all Indigenous people newly diagnosed with HIV, 1/3 are youth (under 30), and 25 per cent of all Indigenous people who currently live with HIV/AIDS are youth (Canadian Aboriginal AIDS Network [CAAN], 2003). With 2/3’s of the Indigenous population in Canada being under 30, the increasing rate of HIV infection among Indigenous people highly impacts youth (CAAN, 2003).

With the high numbers of Indigenous youth becoming infected, it is apparent that one of the main focuses for HIV/AIDS prevention and education needs to be on young Indigenous people. In addition to the United Nations Educational, Scientific and Cultural Organization’s (UNESCO) appeal that HIV prevention education adopts “a cultural approach,” (UNESCO, 2004, AIDS & Culture section) education for youth needs to be developed with active Indigenous youth involvement in all stages of the process.

There is an urgent necessity for awareness and education as to how Indigenous youth can take responsibility for their own safety and well-being in relation to HIV/AIDS. There is a need for “frank, accurate, and consistent information and materials that are relevant to youth and not a reflection of adult assumptions about what they think youth should know (and not know)” (Health and Development Networks [HDN], 2000).

Aboriginal youth should be included in decision-making about the education and programs they receive. Youth need to feel they are respected and that their opinions and experiences are valid. “Young people have important tools at their disposal which must be utilized against the spread of HIV/AIDS: namely an ability to know what will work for them and an ability to communicate effectively with each other” (HDN, 2000). In many Indigenous cultures, children and youth’s perspectives are considered integral to decision-making and they are regularly given leadership roles (SD 87, 2000, Family section).³ Excluding Indigenous children and youth from the process of developing the education they will be taught (particularly if the education subject matter and delivery format is foreign to traditional ways of life) stifles their personal sense of ability, leadership and identity.⁴

Furthermore, Indigenous youth need the opportunity to have this information shared with them by their peers in a cultural context that they can relate to.

In terms of HIV/AIDS prevention and care, adopting a cultural approach means that any given population’s cultural reference (ways of life, value systems, traditions, beliefs, religions and fundamental human rights) [should] be considered key when designing, implementing and monitoring prevention and care strategies, programmes and projects (UNESCO, 2004, AIDS & Culture section).

³ Much of my knowledge on Indigenous ways of life comes from personal experience and how I was raised and taught by my immediate and extended family. “Intangible knowledge [is defined] as personal knowledge resulting from individual experiences. This knowledge is largely embedded in the culture and tradition of individuals or communities” (Ocholla & Onyancha, 2005, p. 247).

⁴ From my perspective based on my experience, Indigenous children and youth being included in traditional “education” is altogether different, because “education” in Indigenous ways of life is not exclusive to institutional settings. Education, teaching and learning occurred every day all the time, in formal and informal situations.

Empowering young people to trust in their experiences and to speak out makes me feel like I am helping to fill a large gap. As a woman whose voice was often silenced growing up, working with and encouraging youth to speak out gives me a sense of fulfillment and validity, and is like coming full circle. In learning about the need for more effective HIV prevention with Indigenous youth, I recognized that the teachings that reach youth well are teachings that are developed in partnership with youth themselves.

In this chapter I have identified three areas that are fundamental in realistically decreasing HIV infection amongst Indigenous youth. These are that:

- Very few HIV prevention programs are geared towards, or inclusive of, Indigenous youth experiences.
- Indigenous youth need to be actively involved in the education of Indigenous youth, particularly on matters dealing with youth social lifestyle (partying, sex, drugs – health related issues).
- A cultural approach is necessary in meeting the realities and experiences faced by Indigenous young people.

THESIS FOCUS

My research question is:

What are Indigenous youth perspectives on the HIV/AIDS prevention programmes that they have delivered?

The interview questions that guided my inquiry were:

1. Do you feel that the peer education you were involved in was effective in educating young people about how to practice safer behaviours and avoid becoming infected with HIV?
2. What drew you to working as a peer educator?
3. Why did you stay involved?
4. Do you feel your work helped you to change your own behaviours?
5. Do you recommend any changes to the workshops you delivered?
6. Were the cultural aspects to the workshops relevant and important?

The goal of my research was:

To find out what space can be created for Indigenous youth perspectives on HIV prevention. By providing recommendations from Indigenous youth on how to empower other young people, my thesis will provide insight for AIDS organizations in decreasing HIV infection among Indigenous youth.

OVERVIEW OF THESIS CHAPTERS

Following this introductory chapter, is a literature review, which reviews the materials that contribute to the emerging field of culturally relevant education in HIV prevention. Chapter Three describes the methodologies I used for this research, and Chapter Four describes my findings. A concluding chapter focuses on recommendations derived from my research.

CHAPTER TWO – LITERATURE REVIEW

This chapter provides a discussion of the literature that is relevant to my research including traditional Indigenous ways of life with respect to health, colonization and its impact upon cultural continuity. The chapter also examines peer education and why it is important for maintenance of healthy lifestyles. I also discuss the types of prevention approaches being implemented in various parts of the world. Each of these topics will be explained and related to each other in order to provide a background and deeper understanding of the contextual dynamics that have an affect on HIV and Indigenous young people.

TRADITIONAL HEALTH AND PREVENTION

Prior to contact Indigenous communities had self-sustaining, advanced and effective health care systems. In their chapter entitled “Medical Traditions in Aboriginal Cultures,” Waldram, Herring, and Young (1997) discuss how health was maintained and nourished and how illnesses were dealt with and understood. Waldram et al. (1997) provide a wide ranging discussion around Indigenous healing and treatments for diseases and illnesses as they are related to supernatural forces. Both Waldram et al. and Krippner (1995) have assessed health care prior to contact, but have not thoroughly explored the role of prevention. I have extrapolated aspects of their writing which touch on preventative actions.

In understanding how medical traditions and health care practices occurred prior to contact, Waldram et al. (1997) have explained that:

scholars investigating this problem depend on a body of mostly fragmentary material evidence that has been pieced together by physical anthropologists and palaeopathologists.... This evidence is then interpreted in the light of current theories and methods in these fields, with reference to contemporary thinking about disease, and by comparison to the health experience of Aboriginal populations.... (p. 23)

Linda Tuhiwai Smith, in her book “Decolonizing Methodologies: Research and Indigenous Peoples,” offers an Indigenous perspective substantiating pre-contact knowledge asserted by Indigenous individuals:

These...accounts are stored within genealogies, within the landscape, within weavings and carvings, even within the personal names that many people carried. The means by which these histories were stored was through their systems of knowledge. Many of these systems have since been reclassified as oral *traditions* rather than histories. (Smith, 1999, 33)

Waldram et al.’s explanation of Western scientific ways of understanding pre-contact health conditions, combined with Smith’s emphasis on “oral ways of knowing” (p. 33) as fundamental systems of carrying forth knowledge, support discussions in this dissertation on what some traditional cultural practices encompass. This Chapter offers a combination of the findings of several authors, (based on the two approaches above: Western science and oral histories), with my own voice as a woman with an Indigenous family

background where oral history has been a source of cultural sustainability.

Waldram et al. (1997) preface their chapter by stating that Indigenous health care practices “developed and adapted to the environmental, economic and political changes wrought by Europeans” (p. 97). This statement is very true and it is important to further recognize that even prior to contact Indigenous knowledge and medical traditions were developing and adapting with social and environmental changes. “Given the universal capacity of cultures to adapt to change, [the] belief” of “cultural retention... versus modernity... represents little more than confused idealism” (Hempel, 2005, p. 1). “Indigenous ... skills, knowledge and attitudes are shared, adapted and refined and therefore change with time” (Ocholla & Onyanacha, 2005, p. 247). The process of modernization comprises previous knowledge and ways of life which become adapted to contemporary realities.

A discussion on health care and the interconnectedness between the spiritual realms with the physical and mental is reiterated in Stanley Krippner’s (1995) article, “A Cross-Cultural Comparison of Four Healing Models.” Krippner’s discussion on forms of treatment and that traditional health practices are still valid today despite their being undermined by Western medicine; this brings to mind how HIV prevention is conducted today. Research validating allopathic health care and rejecting most Indigenous and non-Western teachings results in minimal support for traditional teachings being included in HIV prevention. “Unfortunately, for reasons largely associated with ignorance and arrogance, IK [Indigenous Knowledge] has been neglected, vindicated, stigmatized, illegalized and suppressed among majority of the world communities” (Ocholla & Onyanacha, 2005, p. 248).

Vandana Shiva (2003), in her critique of the Secretariat documents issued by the Convention on Biological Diversity, provides several examples of South Asian knowledge and how “colonial influence...devalued...our biological and intellectual heritage” (Pluralism vs. Hierarchy section). For instance, “instead of strengthening research on safe and sustainable plant-based pesticides such as neem...[the focus was] exclusively on the...promotion of hazardous...chemical pesticides such as DDT...[which] causes millions of deaths each year and has increased the occurrence of pests 12,000 fold” (Pluralism vs. Hierarchy section). She concludes by emphasizing how when Indigenous sciences are actually acknowledged, transnational corporations are often “legitimizing piracy as invention” by claiming “Indigenous knowledge traditions as their ‘intellectual property’ protected through ‘intellectual property rights’ like patents [in which] the indigenous systems get no protection, but piracy of these systems is protected (Pluralism vs. Hierarchy section).

Generalizing Indigenous forms of prevention and health care prior to contact (and still today) should be avoided, plainly due to the fact that “at least 500 major tribes lived in the territory that now comprises the United States” (Krippner, 1995, p. 22). I agree with both Waldram et al. (1997) and Krippner in their discussion around the holistic context of individuals’ lives as integral to the structure of Indigenous health systems. The deeper analysis provided by Krippner identifies how the spiritual realm, which he names as a “transcendent intelligence or process,” (p. 22) in a persons life “inspires devotion and directs behavior” (p. 23) and “directs important life decisions and activities” (p. 23). The holistic nature of spirituality was a part of every day life, and was interconnected with daily beliefs and activities. This had a large impact on the choices people made and

which activities they chose to engage in, and which to avoid.

In recognizing that spirituality, combined with the mental and physical, affect the behaviours of community members, it makes sense that spiritual ceremony, life lived on the land, stories, and so on, contributed to prevention. There were stories that served to model behaviour to children, and those were effective forms of prevention.

The supernatural realm, interconnected with daily activities, such as nourishment, health and illness, and values, such as respect, is presented in the example of “an Apache disease called “nitsch” [which] results from the neglect of nature. An Apache who does not properly salute an owl may suffer from heart palpitations, anxiety, sweating, and shaking” (Krippner, 1995, p. 24). A further example of prevention occurring from strong cultural connectedness is how “the ability to heal and protect oneself from disease or illness was predicated upon the assistance of . . . other-than-human beings” (people who would visit during dreams and were respected as having some responsibility for community protection) (Waldram et al., 1997, p. 101).

I engage in the discussion of interconnectedness of spiritual beliefs with every day life activities to present evidence that cultural practices have always been fundamental to the maintenance of Indigenous health. With foreign exploration, including settlement on Indigenous lands and colonization, a forced disconnectedness from culture gradually took place. This was due to territory theft, land displacement, livelihood limitations and colonial legislation, etc. Continuous resistance, in many forms over hundreds of years, has fortunately resulted in aspects of Indigenous cultures being maintained. These are now being revitalized as well as adapted to contemporary ways of life. The cultural disconnect arising from colonization results in the situation we face today in Indigenous

communities regarding health. Indigenous health is the worst out of all “racially” identified groups in Canada.

Aboriginal people have a level of health that is below that of the general population. Status Indians in B.C. can expect to live 7.5 years less than other British Columbians. For almost every cause of death, Status Indians die at higher rates and younger ages (PHO, 2002, p. 23).

CONTEMPORARY HEALTH REALITIES

Reviving Indigenous teachings is a significant undertaking and an ongoing process. While cultural recovery is occurring in ways in which it can be adapted to and maintained in contemporary society, society faces the immediate reality of poor health in Indigenous communities. In my introductory chapter I presented the appalling statistics on the high rate of infection amongst Indigenous youth (page 9). The risk of HIV infection and the challenge to make safer choices are realities faced by all peoples. The rate of increase of HIV infection in young women in general is on the rise and also among non-Indigenous youth. “In 2002, women accounted for nearly one-third of the new infections in Canada. Even more startling, in the 15 to 29 age group, they made up nearly one-half of all new infections” (Binder, 2004, p. 12). My research examines HIV prevention as it specifically relates to Indigenous youth because there are different needs and multifaceted prevention interventions that are necessary. To date these needs have been extremely marginalized in HIV prevention across Canada. These needs directly involve the aforementioned dialogue of cultural teachings and revitalization in health care.

With the situation having changed today from healthy self-sustaining communities to many Indigenous youth's health being unstable, let us briefly focus on what is happening and summarize why and how youth are becoming infected. (In providing a summary of these questions this will not be a conclusive or definitive answer. It is an overview and cannot cover every aspect.) Development of reservations was one colonial method of limiting Indigenous people's livelihood, such as hunting, fishing, trapping and berry picking. People no longer had access to their traditional food sources, and thus became gradually dependent on colonial-prepared foods or farming. This not only altered diet but the ways of life became more sedentary. People, who were once completely reliant on being active for nourishment and regular movement of camp, were forced to live in areas that have been described by some as concentration camps in Canada. In 1850 government agents began making lists of who belonged to which Indigenous band (Indian & Northern Affairs Canada [INAC], 2003, The Register's Beginnings section). Then in 1951 the Canadian government established the Indian Registry and introduced Indian status cards (INAC, 2003). These cards defined, amongst many things, who could and could not legally identify as Indigenous. Indian status cards are still in effect today and have caused many rifts within Indigenous communities.

Residential schools were created prior to Confederation, but began being administered by the Canadian government in 1874 (INAC, n.d., An Historical Overview section). Indigenous children living on reservations were often forcefully taken from their homes and put into schools so far away that they could rarely visit family or their community for many months and years. The last residential school closed in 1996. The horrific impact of these schools in many ways cannot even be described with words.

Residential schools were often cold, frightful and sullen places where children did not learn parenting skills, but were often told how horrible their Indigenous identity was. Through all of these colonial experiences, children were taught to hate who they were and much about being Indigenous.

There is a small minority of Indigenous peoples who experienced residential school who do not consider their experience to have been damaging. However, when comparing the numbers of individuals who consider their experience to have been positive (because they learned to read or write or did not experience physical or sexual abuse, for example,) to individuals who feel that damage was done, those numbers seem insignificant. Non-Indigenous (primarily White) adoptions of Indigenous children were occurring simultaneously as residential schooling and the outcomes are strikingly similar. “The literature...on adult Indians who have experienced out-of-culture placements as children...indicates that nineteen out of twenty Indian adoptees have psychological problems related to their placement in non-Indian homes” (Locust, 2000, p. 11). The negative experiences far outweigh the positive incidents’ because the abuses struck far beyond being only physical or sexual. The experience of residential school was holistically damaging. Family connectedness, the development of parenting skills, community roles and responsibilities, identity self-confidence, culture and language knowledge, and social values were attacked by the removal of children. “The cluster of long-term psychological liabilities exhibited by American Indian adults who experienced non-Indian placement as children may be recognized as a syndrome. ...Major contributors to the...syndrome” (Locust, 2000, p. 11) are:

- the loss of Indian identity,
- the loss of family, culture, heritage, language, spiritual beliefs, tribal affiliation and tribal ceremonial experiences,
- the experience of discrimination from the dominant culture, and
- a cognitive difference in the way Indian children receive, process, integrate and apply new information. (Locust, 2000, p. 11)

As a result of these community disruptions many Indigenous peoples are affected by residential school policies, whether or not immediate family members attended the schools.

Many people have fought very hard and resisted assimilation and these colonial tactics. There are very humorous and heartwarming stories of children's resistance in schools, and parent's fighting to keep their children at home with them. Resistance occurred (and still does) in many ways, from preserving cultural teachings and values, to protecting the land from development on traditional territories.

While resistance continues the issue of children and youth becoming infected with HIV is a reality. Indigenous children and youth are still continuously taught (through media, schooling, neo-colonial attitudes and messages, etc.) to think of themselves as inferior. Sports teams, such as the Atlanta Braves, books such as "Indian in the Cupboard," popular rap groups such as Outkast, and movies such as Peter Pan, continue to misrepresent Indigenous peoples. The stereotypes include being perceived as either cruel or noble with representations of Indigenous people dressed in loin cloth and speaking, dressing and living a mish-mash of pan-Indigenous cultural concoctions. When

youth are taught to have low self-worth and are disempowered through disconnection from their culture, land and identity, they begin to live in unhealthy ways. “Research and common sense tell us that social factors, including racism and sexism piled on top of stigma, discrimination, and poverty, have more to do with vulnerability to HIV than does individual behaviour” (Binder, 2004, p. 12). Often choice is limited by social factors and the need for survival, and that need sometimes carries risks. Some young Indigenous women survive as sex workers, and are forced into positions of non-consensual unsafe sex. Many women involved in sex for survival engage in intravenous drug use to bury the pain of what they are experiencing, as well as what they have grown up being taught about themselves. Prostitution and sex work compounds the risk of becoming infected with HIV. “Aboriginal women are twice as likely to be infected by injection drug use than by sexual contact” (p. 12). For HIV positive Indigenous youth who are not involved in the sex trade, infection occurs through non-consensual intercourse, drug paraphernalia, sharing of tattoo and piercing needles and consensual unprotected intercourse. Unsafe sex is frequently related to low self-esteem in that young people, usually women, fear rejection from young men if they insist on use of protection (condoms, dental dam, etc).

I have presented my perspectives on “how” and “why” HIV infection of Indigenous youth is so high. I will now engage in what can and is being done to deal with the increasing infection rate amongst Indigenous young people.

PEER EDUCATION

There are several forms of prevention that are offered, though not on a continuous or large scale basis. Sunfire was the only Indigenous HIV organization in BC, and one of a

handful across the country. It was an Indigenous youth-run HIV/AIDS organization that centred around peer-led education workshops. Peer education is a method that came about following its successes delivered by and to homosexual adult males (Ott, Evans, Halpern-Felsher, Eyre, 2003, p. 160). Peer education has a long and successful track record, having been used in agriculture, marketing and community development (Kelly, 2004, p. 140). A style of peer education is the Popular Opinion Leader (POL) approach discussed below. The POL approach is based on behaviour change theory, which maintains that “popular and socially influential members of the target population” (p. 139) are able to influence their peers and reach them by translating “messages into culturally appropriate metaphors, and communicating the messages in a medium to which [their peers] can relate” (Ott et al., 2003, p. 160). Peer educators are usually a specific group of people who are trained by professionals employed in the field. They are “trained in leadership skills, teaching skills and how to facilitate participatory approaches such as role-plays” (Roberts Lamont, 2004). The educators go on to use the knowledge and skills they have learned in order to educate and influence their peers. They often become role models and leaders to their peers. “There is evidence that young people can effectively educate and influence their peers and that participation in a peer education programs [*sic*] may be highly beneficial to the peer educators themselves” (Planned Parenthood Federation of America, 2002, p. 3).

"POPULAR" PEERS

In defining peer education, it is important to identify differences in process. In J. A. Kelly's (2004) article, “Popular Opinion Leaders and HIV Prevention Peer Education:

resolving discrepant findings, and implications for the development of effective community programmes”, he challenges the notion that popular opinion leaders are anything like peer educators. “The POL approach represents a very specific, theoretically based type of peer-based programme” (Kelly, 2004, p. 141). He explains how the POL approach distinguishes a specific audience and then studies and selects who the popular members of that group are. The POL approach then recruits 15% of the identified popular and influential members of that group (p. 143). Kelly provides a table presenting “core elements of the popular opinion leader model” (p. 143) (see Appendix 1). In reviewing this model it has many similar characteristics to peer education, and I disagree with Kelly’s insistence on such a differentiation. I see the POL approach as a more specific and regimented style of peer education, and one that can be followed and repeated by other peer programs (finances permitting).

I do not support the POL approach for an Indigenous youth prevention project, in the format that Kelly has described it. What concerns me about it is the disciplined selection of “popular” members of a group as influential because of their “social standing” (Kelly, 2004, p. 142). Kelly says that “the critical objective...of the POL model, is not merely to enlist peers but to identify and recruit those specific individuals who are the popular opinion leaders within the multiple social segments comprising the target population” (p. 142).

The POL process of differentiation of “social standing” makes me fearful. I find it has aspects of the hierarchical colonial attitudes that have caused marginalization and oppression of Indigenous peoples. In my personal experience in peer education in schools in Vancouver, I encountered what I find to be a mindset similar to Kelly's (2004) POL

view.

I was hired by a school to coordinate a non-Indigenous-specific youth peer group presentation on respect. One of my former Indigenous youth peer educators (from a previous project) attended that school so I asked for her to be involved. Two teachers told me that they didn't think she would be a good peer educator because they felt she was not a leader and they couldn't see her participating. They strongly discouraged me (unsuccessfully) to include this young woman. According to the POL principles as they are presented by Kelly (2004), this young woman would not have been considered as a popular opinion leader. However, this youth turned out to be the best youth peer educator I have ever seen. Had I excluded her because of how she was perceived by these teachers or her peers, she would have lost the experience she gained (self-esteem, skills building, etc.), and we would have missed out on one of the more influential young educators at that conference.

This is not to say that I disagree entirely with Kelly's (2004) project on HIV prevention or his process of conducting it. The point is to present discussion on whether his process is appropriate for Indigenous contexts. Indigenous contexts are not homogenous, and various approaches are followed in traditional and contemporary ways of life. Leaders who specialize in certain skills (politics, sports, carving, Elders) have important places as role models and are often identified as such. However, a value that is held in most Indigenous epistemologies in Canada is that all members of the community have a place and valid voice. No one member of a group is perceived to have a more important voice than another and no one is left out.

From an Indigenous perspective, all youth have the ability to be leaders and peer

educators. We need to treat youth as leaders in order for them to learn to behave as leaders. As a coordinator of an Indigenous peer education project I would avoid excluding youth because they were not considered to be “popular” enough. On the basis of my experience, I argue that the influence of the peer educators has to do more with the coordination of the program and training of them as facilitators than the “popularity” of the youth.

The POL approach according to Kelly (2004) is selective in its audience and in its peer educators. If we are aiming to get a message about basketball to a basketball team, the more convincing message will come from a well-liked and admired basketball player as opposed to a weaker and unknown player. Still, when it comes to youth peer education, and youth self-esteem, it is important to avoid reinforcing marginalization of oppressed youth (such as un-“popular” teens) by showing that only the “popular” people have a valid voice. Peer education is effective because it influences the lives of not only the audience, but more-so the peer educator themselves.

SEX ED APPROACHES

There are two prevalent approaches when it comes to STD/STI sex education programs. These are “abstinence-only education,” and “comprehensive sex education.” In Chapter Four of this thesis I put forward a discussion around fear and HIV. The conversations I had with my interviewees on youth’s being fearful of HIV infection raised the question for me around fear-based education strategies. I asked myself if it is more effective to have young people be afraid of contracting a disease, or if they should be aware of all of the factors involved and make their choices according to that knowledge. Fear-based

education does not paint a clear picture of transmission and disease. It is not that one should be or would be at ease once they have a clearer picture of transmission, but rather that they would be more knowledgeable on how to make safer choices. Fear based education is similar to abstinence-only education which:

teaches abstinence as the only morally correct option of sexual expression for teenagers. It usually censors information about contraception and condoms for the prevention of sexually transmitted diseases and unintended pregnancy...[It] often uses fear tactics to promote abstinence and to limit sexual expression (Advocates for Youth [AFY], n.d., b).

Using fear tactics and abstinence only education to make young people afraid of sex is not only futile but is also “bad science, bad policy, and a blatant violation of medical ethics and basic human rights” (AFY, 2006). The reality is that “70 percent of 18-year-olds [in the US] have had sexual intercourse” (AFY, n.d., a), many young people are experimenting with various forms of intoxicants, and using needles for tattooing and piercing. Abstinence-only programs tend to give very limited information on contraception, often only referring to condoms, and overemphasizing their failure (AFY, n.d., b). Furthermore, these tactics do not address the self-esteem issues that are at the root of why many young people have risky behaviours. A comprehensive preventative education program (such as was practiced at Sunfire) covers a variety of contraception, safer needle and paraphernalia usages, discussion around alternatives to sex and needle use, and open communication around subjects of the audience’s choice. This allows for

young people to make more informed decisions about their choices, and thus be empowered by the knowledge to make that decision.

Sunfire taught HIV prevention according to comprehensive education approaches. This program was unique in its style in that it focused specifically on the experiences faced by Indigenous youth. This was accomplished by the workshops being delivered by Indigenous peer educators and the inclusion of their daily experiences, language, slang, their realities, cultural teachings and worldview. In addition to this example and those discussed previously, it is important to examine prevention programs with marginalized populations outside of Canada. This will enable a clearer picture on how HIV prevention is being delivered in similar contexts, and which strategies are found to be most efficient.

GLOBAL HIV PREVENTION AS COMPARISON

A search of the Academic Search Elite on EBSCO Host Research Databases reveals cross-cultural articles on HIV prevention. It is important to include a comparison of prevention programs around the world, but at the same time to focus on HIV prevention with marginalized communities within these countries to provide the most similar types of experiences to my research. The examples that I've included which are the most relevant to my research are the studies and projects with ethnic minorities in China, with Haitian American youth, and with the Roma peoples in Bulgaria and Hungary. In understanding what has and hasn't worked with HIV programs and marginalized groups outside of Canada I can compare contexts, experiences and recommendations to the programs I have studied and been involved with in Canada.

I have chosen to look at international marginalized communities' HIV prevention

programs as a comparison, because marginalized communities are vulnerable and generally experience a “lack [of] access to preventive health care,” (Malow, Jean-Gilles, Devieux, Rosenberg, Russel, 2004, p. 127) as is experienced within the Indigenous population in Canada. Further generalities include socio-economic contexts that create differences in risk factors as compared to the majority population within the country; and “inadequately targeted prevention messages, and cultural differences between the health care system and the populations it serves” (p. 127).

In my comparison and analysis of various international prevention intervention studies, I will not describe in detail the socio-political-economic disadvantages faced by the communities receiving the intervention. I will highlight the unique aspects of the interventions, as well as critically examine them, for purposes of exploring and revealing what would work and what wouldn't with Indigenous HIV prevention interventions in Canada.

Prior to engaging in discussion on international programs for marginalized populations, the difference between Indigenous and minority should be briefly addressed. Indigenous populations face different forms of oppression than those of minority communities, although there are experiences that are similar. This difference has to do with the displacement within one's own territory. Minority communities have a land base to connect to somewhere in the world (which may or may not be colonized,) but it is outside of the Indigenous territory on which they are residing. The situation faced by Indigenous communities is referred to by many Indigenous political activists and scholars as “Fourth World”. George Manuel (1974), former Shuswap Chief and first president of the National Indian Brotherhood, in his book “The Fourth World: An Indian Reality”

coined this term. Dr. Richard Griggs (1992) from the Center for World Indigenous Studies defines this as “nations forcefully incorporated into states which maintain a distinct political culture but are internationally unrecognized”. Therefore, lessons from effective interventions for minority communities might not be entirely applicable to Indigenous experiences. It is still useful however to examine these programs in order to understand aspects that may be relevant. Robert Malow et al. (2004), the author of the Haitian youth study, discusses this as “translational research” where “interventions demonstrated to be effective in one population are adapted to a different cultural group” (p. 130).

HAITIAN AMERICAN YOUTH

This article discusses an ongoing mainstream HIV intervention program, entitled “Becoming a Responsible Teen,” which was “culturally adapted” to target the Haitian American population in Miami, Florida.

The aspects of the prevention intervention that the paper discusses which make it “culturally competent” (Malow et al., 2004, p. 127) are: connecting their prevention with health care and services geared towards the Haitian community; involvement of members of the target population; and using the community organizations that were already set up in the community to recruit participants and deliver the intervention (p. 129).

The authors go on to discuss the contextual factors facing Haitian youth, which impact HIV prevention. “In order to reduce the stigma associated with HIV for Haitians, the HIV epidemic should be addressed within a context of overall health and overall social, emotional and physical wellbeing rather than HIV alone” (Malow et al., 2004, p.

131). The same situation exists for Indigenous youth in Canada. As I have mentioned, HIV/AIDS in the Indigenous community is directly related to colonization, racism, poverty, and other socio-economic and political forms of oppression.

For these same reasons, and following focus groups and input from Haitian youth workers, the Haitian youth study project found components that should be included were a discussion of: “(a) natural remedies used by Haitian families in promoting health, (b) the historical aspects of denial about HIV/AIDS in the Haitian community..., and (c) acculturation and the stresses it places on Haitian families” (Malow et al., 2004, p. 130).

The aspects that relate with and support the HIV prevention techniques revealed in Chapter Four of this paper are the importance of discussion around both Haitian traditional healing practices, and acculturation. Discussion in an Indigenous context would focus more on colonization on Indigenous territories, which precedes acculturation into Canadian society. Discussion around HIV/AIDS being a taboo subject and its denial is also important in Indigenous HIV prevention, but was not discussed as frequently by my interviewees as was colonization, cultural oppression and returning to traditional teachings.

The authors of the Haitian youth’s study also included the same “HIV 101” content that most prevention programs follow. The article discusses other aspects related to the prevention, many of which are peripheral to the actual delivery of the “skills building intervention” (Malow et al., 2004, p. 131) which this research study is focusing on. Therefore I have left these aspects out of this discussion as they would take me on a tangent into HIV prevention program coordination.

ETHNIC MINORITIES OF CHINA

The prevention work conducted by authors Wang and Keats (2005), as discussed in their article “Developing an innovative cross-cultural strategy to promote HIV/AIDS prevention in different ethnic cultural groups of China” is unique and strongly tied to the communities it serves.

The project was established following research on prevention programs with minority communities in the United States, and research on Chinese ways of life. Their research was exceptional in that there had been no previous projects of this sort with ethnic minorities in China.

The project was well structured and organized. It consisted of recruiting volunteers, training these volunteers as peer educators, recruiting more volunteers as recipients of the peer-education, referred to by Wang and Keats as the “peer-diffusion” (p. 874) process, and a control group of volunteers who did not receive peer education. These three groups were repeated in three ethnic communities, the Yi ethnic group, the Tibetan ethnic group, and the Han majority cultural group (Wang & Keats, 2005, p. 876). The socio-economic circumstances faced by the Chinese minorities are devastating. In comparing this project to my research a similarity is in using intervention techniques for hard-to-reach individuals and minority communities where mainstream interventions are not working. Wang and Keats discuss the mainstream prevention that exists in China, and this brings to mind the fear-based tactics I discussed earlier. The mainstream prevention uses, according to the authors, “threatening moralistic official messages... with their uniform prescription of officially approved media materials and messages” (p. 875).

The challenges faced by the project were language barriers, as “Chinese is not

widely read or spoken” (Wang & Keats, 2005, p. 875). The three ethnic groups recruited to the project each spoke their own native language. The languages were not written languages and “interpersonal oral traditions dominate the process of message formation and its diffusion in semi-literate people and in the ethnic minorities” (p. 875).

A further challenge the organizers faced was geographic location. Participants were situated in a “remote and impecunious mountainous area” (Wang & Keats, 2005, p. 876). HIV spreads quickly in these areas where people do not have access to or funds for condoms. Furthermore, condoms were not a part of the culture, and thus the project had to focus strongly on how to get participants to even consider using a condom.

The project developed intervention techniques according to the lived realities of the different ethnic groups involved. Oral communication became the central mode of delivery. The volunteers participated in developing four “role model stories... to use local languages, modified as required by the participants themselves, in an indirect, non-moralistic, style adapted to the local cultural tradition” (Wang & Keats, 2005, p. 876).

Remoteness, small communities, oral communication and minimal education are aspects faced by Wang and Keats’s (2005) project that also exist with many Indigenous communities in Canada. For these reasons lessons can be learned from this project and applied to Canadian Indigenous HIV interventions.

Humour was a common aspect of communication and was therefore integral to the intervention. “Sex-related humorous story-telling is a ubiquitous and popular communication mode in these communities” (Wang & Keats, 2005, p. 878). This is another popular dynamic to Indigenous ways of life in Canada, and an aspect that definitely needs to be a part of the prevention education.

As described by Wang and Keats (2005) drop-in centre room was created for peer educators to get together and counseling services were available. The intervention stories had other relevant aspects which would apply to Indigenous prevention. Because the communities were oral and language unanimity didn't exist, the educators made "stickers highlighting key points from the stories... [and used] simple language" (p. 879), and "colloquial and slang local languages" (p. 880). They posted a "condom cartoon and the address and hours of the drop-in centre" (p. 880) on the trishaws (cycle rickshaw) that many of the peer educators drove. This brings to mind the stickers, cartoons and testing site information that Sunfire created to distribute to workshop participants and youth in the community. Peer educators wore "a badge made of red ribbon" (p. 880). In borrowing this idea, Indigenous interventions could distribute some wearable, yet fashionable and "cool" object (pin, t-shirt, baseball hat, etc.) to peer educators to wear at their leisure, to initiate questions from their peers and initiate discussion around HIV/AIDS.

More tactics from the Wang and Keats (2005) project are the lessons learned from peer education, as identified earlier. Wang and Keats relay that:

the approach taken did not take a punitive or moralistic stance, nor did it set out to criticise [*sic*] the norms of sexual behaviour. ...the approach of 'friend to friend' ensured that the participants did not perceive the intervention as something imposed upon them by outsiders. (p. 887)

The authors discuss the "empowerment of the participants" (p. 887), the sense of responsibility they gained, and their identity as educators, as key factors leading to the project's success. These aspects are also noted as significant to the interviewees of my

research. This is discussed in the Chapter Four of this thesis. As is also discussed in that chapter, the peer educators, or “direct training groups” as the authors call them (p. 888), are the members who are the most substantially affected by the prevention. They were selected, trained, involved in the development, given the responsibility of training others, and embraced an identity of being a peer-leader. The same dynamics occurred with my peer educators at Sunfire, and this is why I am advocating that youth who are considered “at-risk” are the very youth who should be recruited as peer educators themselves.

ROMA PEOPLES

The Roma people of Bulgaria and Hungary face such high levels of discrimination and oppression that they have been completely left out of studies on HIV infection rates. “Although widespread social health problems have been documented among Roma men and women, little is known about cultural norms, attitudes and practices related to HIV/STD risk” (Kelly, et al., 2004, p. 232). The article by Jeffrey Kelly et al. is one of the first studies on the issue of HIV risk among the Roma. The article is a summary of a study conducted to determine sex-related attitudes and perceptions of HIV risk among Roma men compared to Roma women. As relayed by the authors, it is the first of the necessary steps towards establishing prevention programs in Roma communities. With the study examining aspects that *precede* the implementation of preventative measures, there is still relevance to my research. This study is pertinent to my research in that it highlights the devastating oppression that marginalized communities face, and how HIV/AIDS is a high risk to communities who live under such realities.

Although the Kelly et al. manuscript opens doors for HIV awareness and

prevention in Roma communities of Eastern Europe, I take issue with the approach they use with their research. In closing their article they state that “HIV prevention programs” and “endorsements” (Kelly, et al., 2004, p. 245) must include community members. However, in the design and implementation of their research study they have excluded the very community members whom they are later suggesting be involved.

In describing their methods of developing an “interview guide” they state that it “was developed by a multidisciplinary team that included sociologists, psychologists, ethnographers, and NGO staff with ...substantial experience working in ...Roma communities” (Kelly, et al., 2004, p. 237). The translation and data analysis was conducted “by professionals” (p. 237). There is no mention of the involvement of Roma peoples. It concerns me that Kelly et al.’s intentions might not be so much to empower the community by making Roma peoples participants in the research, but rather to use “popular” community members to achieve status and support for the POL model which I discussed beginning on page 23.

My concerns about Kelly et al.’s intentions are advanced by the debate that took place between Kelly and a POL project in London where sexual risk behaviour change success was not found. Kelly accused the London project of not following his POL elements appropriately (see Appendix 1) (Kelly, 2004). The London project argues that the POL approach is not as globally applicable as Kelly purports (Elford, 2004).

In the Roma article Kelly et al. are on one hand advocating peer leadership and involvement as “especially powerful” (Kelly, et al., 2004, p. 245) but on the other hand they do not take this approach in the design of their own project; an approach that could reveal a much more profound view on Roma experiences. Because of this exclusion I

find the underlying attitude behind the Kelly et al. article, as compared to the Wang and Keats (2005) article (on minorities in China) and the Malow et al. (2004) article (on Haitian youths), reveals some signs of superiority and condescension. Kelly et al.'s goals are compassionate and include a desire for the greater good of the communities they are working with, but their strategy, as is revealed through their manuscript, is slightly curbing of communities' self-determination.

This article was a difficult read, as the ways that Roma people are forced to live is so horribly oppressive. The conditions of impoverishment of the Roma are very similar to how many Indigenous peoples in Canada are forced to live. However, rather than being displaced upon one's own territory, the Roma are a people who live without a territory to call their own. The study by Kelly et al. is a remarkable step forward in bringing awareness to how small ethnic minority communities are often marginalized within states, and how this impacts life standards and health conditions.

In marginalized communities where individuals do not receive equal education, people are highly misinformed, and misconceptions about HIV transmission are rampant. Although Kelly et al.'s (2004) paper is a study on attitudes impacting risk, the authors do discuss how prevention might begin. The provision of information "about behaviours that confer risk versus those that do not" (p. 244) is an initial step. A breakdown of the myths and stereotypes of risk is needed, similar to the needs of Indigenous youth. This includes the belief "that one can tell by appearance whether a partner poses risk and the linkage of AIDS to images of physical debilitation" (Kelly et al., 2004, p. 244). The gender relations between Roma men and women indicate that different prevention education and interventions are needed for each group. Roma men, according to the study, tend to be

more sexually dominant and controlling in relationships. The study also contends that Roma men in Hungary and Bulgaria are generally highly sexually promiscuous, whether married or not, and women are expected to be virgins until marriage. Once married, women are to remain monogamous. While discussing preventative measures that need to be taken, Kelly et al. emphasize the importance of changing men's attitudes towards condoms and creating new norms in this regard. They go on to express the need for women to have access to health care, women's empowerment in relationships, and they explain the socio-economic and political crises that perpetuate and emphasize poor health among the Roma people. I agree with the authors that these are "critical dimensions of HIV prevention programs in Roma communities" (p. 245), as I have highlighted these similar conditions that influence the infection rates of Indigenous youth in Canada. The contextual issues affecting high infection rates in such marginalized communities are undeniable. In terms of prevention, the authors recommend the same point that is resonated in all of the other studies, including my own, on minority and marginalized populations, that "culturally appropriate HIV prevention programs must reflect the input, representation, and involvement of people from the... community itself" (p. 245). The article presents numerous issues which need to be tackled in the face of the surmounting AIDS crises in Roma communities of Hungary and Bulgaria. An important approach that the article omits is the lesson learned from the previously discussed Wang and Keats (2005) study on ethnic groups of China. They present how a more immediately beneficial outcome results when focusing on the realistic and present circumstances lived by individuals. Attempts at changing social constructs, such as attitudes on gender relations, is a considerable task that needs to take place over a much longer period of time. Sexual

promiscuity and social and community constructed dynamics are not judged by Wang and Keats. Kelly et al. (2004) do not however suggest imposing foreign gender-relation attitudes upon the Roma peoples as a solution, but my point is that this is a position they have omitted in their article. They do respectfully go on to acknowledge that the dynamics are such that men discuss sex with other men (not with women), and “women talk primarily with other women within their trusted friendship circles or networks. Therefore, HIV prevention interventions within these natural social networks constitute a promising strategy” (p. 245).

The Kelly et al. (2004) article then enters into a discussion supporting the same Popular Opinion Leader concept that Kelly (2004) stands by in his other article “Popular opinion leaders and HIV prevention peer education.” The Kelly et al. piece states that, “AIDS prevention endorsements originating with respected leaders of [the] community social networks may be especially powerful for changing risk behaviour attitudes, norms, and behaviour” (Kelly et al., 2004, p. 245).

My philosophy of education, and in this case, preventative health education, is contrary to Kelly’s (2004) in this respect. In his two 2004 articles Kelly has discussed prevention interventions and education as effective when delivered according to a hierarchical power structure. He has first argued that only “popular” members of groups have the ability to influence their peers. I argue that this reinforces the power dynamics that create low self-esteem in many marginalized youths - that they are not “cool” enough, or popular enough. Then in his Kelly et al. article on Roma peoples and HIV vulnerability (Kelly et al., 2004), there is a subtle air of the-outsider-knows-best attitude in the design of their research, and that is neo-colonial and oppressive.

ALTRUISM

The study by Mary Ott et al. (2003), entitled “Differences in Altruistic Roles and HIV Risk Perception Among Staff, Peer Educators, and Students in an Adolescent Peer Education Program” is a study very similar to my own, but does not have the culture and identity focal point of my research. The purpose of Ott et al.’s research was “to examine how adolescent peer educators understand HIV prevention messages and their role as peer educators in an HIV risk reduction program” (Ott et al., 2003, p. 159). The investigators interviewed 21 people in total with six being peer educators. Different from my study, they chose to examine the different categories of peer educators, staff, and audience members (the “peer diffusion” group, according to Wang and Keats, 2005). This resulted in an analysis of the effects of the peer education on each group involved in the intervention, and was more of an *evaluation* of the process of peer-based education. Similar to my own research, they have discussed what peer education is, why it is important in terms of preventing HIV, the need of social responsibilities for youth, and what young people believe regarding transmission and how they feel about their prevention work. The authors mention the positive aspects of peer education, such as “reaching difficult-to-access populations” (p. 160) and using youth-friendly language. I add to this record that peer-education is also effective in participating in the revitalization of traditional teachings and cultural identity. The authors express the urgency for their research by stating that “no studies have specifically examined *how* adolescent peer educators understand, communicate, or prioritize risk reduction messages” (p. 160). Risk reduction for Indigenous youths is two-fold. Cultural connectedness is so much a part of Indigenous identity and sense of self, that prevention teachings ought to go hand in hand

with culturally relevant messages. The discussion in the Ott study about the responses from the peer educators is the component of their essay that is most relevant to my work. Ott et al. highlight the strong impact that peer education has on the educators themselves. They refer to this effect as developing "altruistic role identities" in the youth, which they define as "a value placed in helping others" (p. 164). In Chapter Four of this paper I discuss how the youth that I interviewed had a loss of their sense of identity when the Sunfire project terminated. I discuss how being a participant in the Sunfire project created a feeling of responsibility for the youth that became a part of their (and my own) sense of identity. "We consider a role to be a defined task in society, and a role becomes an identity when people define themselves predominantly in terms of performing that role" (p. 164). The altruism aspect is one that is motivating to peer educators, and to myself as the researcher it was poignant and inspiring. The youth peer educators in the Ott et al. study, as well as myself, were guided by altruistic motivations.

Another point that I would like to acknowledge in the Ott et al. (2003) study, and that I make in this paper, is that above all, young people need and want responsibility. Traditionally in Indigenous communities all members, including children, youth and Elders, had known and understood roles and responsibilities. Furthermore, the individuals who should be recruited into peer education programs are the youth who are considered most "at-risk" of unhealthy lifestyles. Being "at-risk" (however one chooses to define that) might not make them popular within their peer groups, as suggested by Kelly (2004), although in some cases it might. Regardless of popularity, the focus should be to involve people who face some level of risk, which more often than not, means they come from marginalized groups. Once given the opportunities to learn and teach others, young

people who face risk themselves frequently take on "altruistic" roles and sense of responsibility and turn their own lives around, while encouraging their peers to do the same.

The peer educators' lives have changed from working in a cafe and getting stoned all the time, to getting involved. All of a sudden it's like watching a flower blossom. They're so into the feeling good about doing something positive. (Ott et al., 2003, p. 164)

The above articles and critical discussion reveal that communities must be involved in their own prevention interventions. Young people and members of the same cultural groups have the unique skills and abilities necessary to reach their peers. The altruism study reveals that peer education has the effect of not only impacting the lives of those receiving the intervention, but even more-so the lives of those delivering the teaching. Youth-to-youth and culture-to-culture forms of peer education are so valuable that in combining these two we can make an even more profound impact upon people's well-being. This includes partaking in revitalizing endangered cultures and identities.

CULTURAL REVITALIZATION OR SUICIDE RISK

In discussing the importance of participating in the rejuvenation of Indigenous cultures, I am compelled to include a discussion on the connection between culture and youth suicide. A very unique study on the effects of cultural connectedness of Indigenous communities to the suicide rates of youth within their communities was conducted by

Chandler and Lalonde (1998). Their article “Cultural Continuity as a Hedge Against Suicide in Canada’s First Nations” discusses how suicide becomes a realistic possibility in peoples lives when they are unable to perceive themselves as continuous (p. 208). They describe continuity as being able to see oneself throughout the various stages of life, with a continuous understanding of who “we have once been, and are now in the process of becoming” (p. 193). The article reaffirms the “old news” that “suicide rates [are] dramatically higher for young persons, and for those whose culture is under siege” (p. 194), thus explaining why suicide rates for Indigenous peoples in Canada are three to five times higher than non-Indigenous peoples (p. 201). The authors examine markers of cultural continuity (including land title, self-government, educational, police, health and cultural governance) and contrast the degree of these markers to the rate of suicide in various Indigenous communities. In their discussion regarding cultural practices, the authors explain that given the Canadian legislation that has so disrupted Indigenous lifeways,

much of what remains is not so much continuous cultural life, as an attempt to reconstruct it. As such, our criteria for what could count as continuity needed to be expanded to include evidence of efforts on the part of communities to preserve, rebuild or reconstruct their culture by wrenching its remnants out of the control of federal and provincial government agencies (Chandler & Lalonde, 1998, p. 209).

They cleverly describe this process as “cultural rehabilitation” (p. 209). This fascinating and eye opening study exposes how communities who’s governance over their own

matters is more solid have “dramatically” lower rates of youth suicide (p. 215).

The necessity for cultural rehabilitation and revitalization is validated by the Chandler and Lalonde (1998) study. Not only are youth at higher risk of HIV due to the lack of cultural connectedness and sense of loss and displacement from identity confusion, but suicide becomes a serious risk as well. It is no coincidence that two of the Sunfire peer educators are also key members of the annual Aboriginal Youth Suicide Prevention Walk (<http://www.theyouthsuicidepreventionwalk.com/>). Indigenous youth peer education can be an amazing tool towards building the renewal and re-strengthening of Indigenous cultures, and not only help decrease HIV infection, but also take part in minimizing youth suicide rates.

In this chapter I have reviewed literature on traditional prevention practices and how religious beliefs and worldview were intricately connected with choices and ways of life. I then discussed how colonization and government legislation created situations where Indigenous ways of life were oppressed. Indigenous people’s health began to suffer and has resulted increasingly high infection rates of Indigenous youth. My proposed solution to addressing infection is Indigenous youth peer education. I presented differing approaches to peer and STD/STI education. This chapter then presented examples of HIV programs in international minority and marginalized communities which face similar contextual circumstances to Indigenous communities in Canada. I concluded with a discussion on the importance of peer education and the profound impact that it can have on peer educators themselves.

CHAPTER THREE - METHODOLOGY

This study was conducted according to qualitative research methods, using in-depth individual interviews and using a semi-structured questionnaire as a guide. My analysis was based on anti-oppressive, feminist, critical, and Indigenous theoretical processes. These form my personal epistemology and directed my research process. Relationships are the foundation of these four perspectives, particularly anti-oppressive research. My analysis drew upon tenets of each of these theories in order to meet my research question on Indigenous youth perspectives on peer education and HIV prevention. I followed aspects of these theories in particular because these features support my values on the importance of the maintenance of difference and the promulgation of Indigenous self-determination.

QUALITATIVE PROCESS

The goal of my research was to find out from youth how they personally feel about the HIV prevention programmes they had delivered. I wanted to know if they felt the peer-education they were involved in was effective in educating young people about how to practice safer behaviours and avoid becoming infected with HIV. In order to answer these questions I searched for the contextual issues that impinge upon that question, such as: What drew you to working as a peer-educator? Why did you stay involved? Do you feel your work helped you to change your own behaviours? And, do you recommend any changes to the workshops you delivered?

My research topic involves three main areas that I explored in my interview questions: 1. Indigenous teachings, 2. youth realities and concerns, and 3. peer education.

I asked the youth questions about these three areas, such as how they feel about Indigenous cultural content being involved in the workshops, and if they think this will reach Indigenous youth more. I asked them how they feel about doing what they do as young people themselves, and how they feel about teaching to other youth.

In looking at how the participants understand and frame their own experiences as Indigenous youth peer-educators, the methodology I used for my research is qualitative. Susan Strega (2005) refers to qualitative research as being “the systematic analysis of socially meaningful action in order to arrive at understandings and interpretations of how people create and maintain their social worlds” (p. 206). Qualitative research searches to understand the world based on context and give insight into the lives of people as told by themselves. In my work with the youth I interviewed, my specific focus was to understand their “world” as it existed in relation to their roles as Indigenous HIV peer-educators. There is a small number of youth across Canada who have the skills and abilities of the youth I interviewed. I learned this when I worked at Sunfire and I would call AIDS organizations across Canada asking to be put in touch with any Indigenous ASO’s that they knew of. I kept being referred back to my own organization.

As I mentioned, my approach in this research has included a combination of anti-oppressive, feminist, critical theory, and Indigenous processes. Although many research methodologies can be used in anti-oppressive manners, I will explain how my research focused specifically on working within the anti-oppressive principles possible within qualitative methods. My research met “the anti-oppressive and empowering possibilities of qualitative methodologies” (Potts & Brown, 2005, p. 282) by working to remove as many “power over” dynamics as possible from the interviewee-researcher roles, and to

provide a channel for the voices of the youth who live the experiences they were sharing with me. It is my intent not only to empower the youth that I have worked with, but also to strengthen myself in this process. In empowering the youth I worked with I focused on achieving this through how I spoke to and connected with them during the interviews, and how I respected their voices in relaying their messages.

“In anti-oppressive research, we say that ‘we do not begin to collect data in a community [until we have built relationships]’ (Potts & Brown, 2005, p. 263). From my teachings and my Indigenous family background I have learned that the building of relationships is a protocol in Indigenous communities. The relationships I built with the youth has involved each of us learning from one another. My relationship with most of the interviewees began during my time working at Sunfire (in 2003-2004). As the coordinator of Sunfire I involved the youth members in as many aspects as possible in my role, such as coordinating activities and attending community functions on behalf of the project. When the members requested a snowboarding trip I told them that I didn’t have time to organize it, but would help them if they did the leg work. One youth took the initiative and with my guidance made all the logistical arrangements for the entire group. Among the other areas the youth participated in organizing at Sunfire were planning the group dinners by arranging the food lists, making sure all the proper equipment was available, making contacts, cooking and cleaning up. Occasionally they would participate in planning their travel and accounting for the money expended. They also helped develop the HIV prevention giveaways which included a condom, stickers, HIV testing site information, chocolate kisses and lollipop suckers. During the interviews several of the youth wanted to know about my academic background and how to go about doing

what I have done. This was pleasantly unexpected. I was delighted that by my simply involving the youth in my research they were being inspired to pursue post secondary education.

My learning from young people has been ongoing since I began youth-work in 1999. I have learned about the strength of spirit despite facing many struggles, as well as the general challenges of being a teenager. Young people have strong beliefs, combined with insecurities, combined with resilience, combined with humour. They also have an amazing diversity in points of view, opinions and experiences. Among the things I learned from the youth I interviewed for this research is the empathy and compassion that young people can have for their peers, while at the same time experiencing fears from being judged by those same peers whom they are empathizing with. The peer-educators I worked with have the unique ability to find humour in the face of adversity, to work with whatever they have to make a situation work for themselves, to face discrimination and oppression and still have the ability to voice their concerns and speak for what they believe in. Youth's varying styles and levels of resilience is what enable them to be this way.

Even when considering many of the negative circumstances in which youth develop, (e.g., poverty), youth *do* exhibit competency in a wide variety of behavioural and mental health outcomes. This exhibition of competence in spite of adversity has been conceptualized as resiliency by a number of researchers (Arrington & Wilson, 2000, p. 222). Resilience [is] a process [that is] fostered by...protective processes [such as] youth's relationships with...family, school,

community, [cultural connectedness, environment, etc.]. (Arrington & Wilson, 2000, p. 225)

In discussing the importance of building relationships with my interviewees for my research, I also want to acknowledge the power dynamics involved. I was the coordinator of the project in which the youth were volunteers, and was therefore in a position of “power over” the youth. Regardless of my views on the abilities and roles of the youth and my attempts to minimize my position of having “power over,” this was still the context of our relationship. Our relationships continue to be influenced by these initial roles, such as my being an ongoing reference for the youth. I made as much effort as possible to involve the youth and engage with them in ways which minimize the position that I was in. I attempted to do this by using open-ended questions and by encouraging the youth to provide me with critical feedback on the interview process. I practice talking and listening in a manner so as to respect the interviewees’ time, knowledge, experience and realities. “Through ... listening, one becomes aware of the construction of multiple interpretations and multiple truths. ... By paying attention and listening, we become increasingly aware of contexts, histories, and social dynamics” (Potts & Brown, 2005, p. 272). In practicing anti-oppressive qualitative research it was important for me to use every possible outlet to minimize the power imbalance. Listening was one of the outlets I used. This helped me to remain open to various perspectives and experiences that led the youth to becoming and remaining HIV peer-educators.

In line with the anti-oppressive feminist values I strive to follow, my method of conducting research and generally interacting with youth involves challenging the status

quo treatment of young people as “Other.” I have sought to find out the background circumstances that my interviewees face, and which frame how and why they are involved in this work. “Feminism... provides alternative ways of thinking about social reality” and critiques the practice of “othering,” which has placed “women, people of color, and sexual minorities” as objects who are treated as inferior (Hesse-Biber, 2005, p. 26). Young people, and particularly Indigenous youth, are marginalized members of society who’s voices are silenced and ignored. Feminist perspectives seek “to create contextualized and partial truths and avoid the absolutes that have historically oppressed women and other marginalized peoples” (p. 26).

I also bring forward a critical theory outlook and analysis to my work.

Critical theorists ... base their concerns on the historical inequities produced by [the] rigid view of knowledge [deriving from] absolute Truth. ... Critical theory seeks to reflexively step outside of the dominant ideology (insofar as possible) in order to create a space for resistive, counterhegemonic, knowledge production that destabilizes the oppressive material and symbolic relations of dominance. (p. 31)

In addition to my anti-oppressive feminist approach, aspects of critical theory are also integral to my worldview. “Absolute Truth,” (p. 31) as it would apply to my research, involves the socially constructed hierarchy of thought and the application of this thought to social power. In Chapter Two (page 15) I discussed the marginalization of Indigenous knowledge and how allopathic medicine is dominant. Western science, medicine and

Western European worldview is notoriously held as “absolute Truth.” The “historical inequities” (p. 31), produced by “absolute Truth” comprise Indigenous experiences of land and cultural displacement, language decimation, and social imbalance.

The theories I adhere to, and which I used in this research, represent the path I walked along in conducting my research. On this journey I had the objective of voicing Indigenous youth HIV peer-educator perspectives and helping to create opportunities for both Indigenous and youth validation. My very specific aim is to create space for the inclusion of Indigenous youth voice in HIV prevention education.

My perspective is further influenced by Margaret Kovach’s (2005) discussion about Indigenous research in her article “Emerging from the Margins”. She states that as Indigenous researchers and allies it is important to consider “indigenizing a Western concept such as research” (p. 25) and we should be asking ourselves the following questions: 1. Is the methodology respectful to culture and community? 2. What are collectivist ethical considerations? 3. Who is driving the research and what is the purpose? Kovach says that non-Indigenous researchers should also ask: 4. Am I creating space or taking space? (p. 26).

I ask myself all of these questions, placing myself between both worlds of Indigenous researcher and non-Indigenous ally, given my blended Indigenous and non-Indigenous family backgrounds. In response to Kovach’s (2005) questions:

1. My methodology is respectful to culture and community in that I have asked the youth to provide their perspective on what is needed for Indigenous cultural inclusivity. We discussed the diversity of cultures in Vancouver, and

ways to include this. I have attempted to avoid imposing one cultural perspective on them, although my own cultural identity is reflective in how my views are parlayed in conversation. I believe that a person can never be objective, as our opinions and perspectives are always laden with our position in the world, our culture(s), our racialized place in society, etc. In acknowledging my place and working to create a space where the interviewees can safely share their perspectives, my process is respectful to community.

2. Collectivist ethical considerations are whether I have expressed the youth's interviews appropriately, as well as protecting their confidentiality.
3. The youth and myself are driving my research, and it is intended ultimately for youth and Indigenous organizations, such as those that my interviewees are affiliated with. The purpose is to improve HIV peer education.
4. I feel I am creating space with this research. I am acknowledging my interviewees experiences as unique and am creating an opportunity for their perspectives, based on their distinctive experiences, to be expressed in a format that will impact other young people.

I have expressed a combination of theories which my shape my epistemology. This is my view of the world which guides my research project. In summary of the aspects highlighting my worldview, I emphasize that youth and children are central in Indigenous communities, and that the HIV education that is being geared towards youth needs to create spaces where youth are central in the design and delivery. Youth and

Indigenous experiences are often undermined and marginalized by Canadian society. Examples are how in May 2006 the Federal government reneged on the landmark Kelowna Accord which was an agreement to address the Indigenous socio-economic gap “representing a \$5.1 billion dollar investment in Aboriginal communities” (Union of BC Indian Chiefs, 2006), and in April 2006 the Vancouver City Council eliminated the Youth Advocate Position:

“[Vancouver City Councilor Tim] Stevenson said he noted the irony of [City and youth advocate Sheila] Davidson losing her job on the same day former judge Ted Hughes blasted the provincial government for its cuts to childcare.” ... ‘It’s a tragic irony that on the very day Ted Hughes confirms the need for independent advocacy for children and youth, Vancouver made a decision to move in exactly the opposite direction’.” (Howell, 2006, p. 13)

When Indigenous youth’s concerns, self-esteem and needs are considered less important by mainstream society their overall risk behaviour increases. Consequently, “each of the six markers of cultural continuity⁵ ... proved to be strongly and significantly associated with reduced suicide rates” (Chandler & Lalonde, 1998, p. 215). Youth need to be seen not as *future* leaders but as *current* leaders and active members of society.

⁵ Which are land title, self-government, education, police, health and cultural governance, as discussed in Chapter Two of this thesis on page 43.

RECRUITMENT

In total, I interviewed six youth, five who lived in Vancouver while they were peer educators and one from the Okanagan region. I began my recruitment of interviewees by emailing the Sunfire youth group in a mass email to find out if they were interested in participating. I heard back through email from five (of the eight) people I emailed saying that they would be interested in participating. I then made follow-up phone calls to each of those five youth to tell them the topic of my research, and how the interview process would work, including the concept of informed consent. I let them know that they had the right at any time to withdraw, and that their decision to decline or participate would not in any way affect their relationship with me. I also offered them the choice to be interviewed by a third party. Only one youth had a question about what being interviewed by a third party would consist of, but she did not want to do it. This indicated to me that this youth was more comfortable in doing the interview with me, who she was familiar with, than with a stranger. I interviewed four of those initial five youth. The fifth person (from the recruitment email) was too difficult to arrange a meeting with due to her busy schedule. I then made several attempts to phone another Sunfire youth who I knew did not have email or voice mail. When I finally reached her I told her about the interview process, as described above. She agreed to participate. Then I used the snowball method to recruit more youth:

When a population is widely distributed or elusive snowball sampling may be the only way of obtaining survey data. In this approach initial contact may be

made with a member of the population who will lead the researcher to other members of the same population. (Williams, 1993, p. 87)

I emailed a former colleague at a local Indigenous HIV/AIDS organization, Chee Mamuk at the BC Centre for Disease Control. She put me in touch with the youth in the Okanagan who I coincidentally had met the previous year at a conference. She also put me in touch with the Assembly of First Nations HIV/AIDS Coordinator, who I had met at that same conference⁶. The coordinator continued this trail of putting me in touch with organizations across Canada. I interviewed one of the youth from these contacts (the youth from the Okanagan) but the others were too difficult to contact and connect with.

The Okanagan youth was harder to telephone because he did not have a telephone number. We made plans over email for him to phone me collect. We were still unable to connect that way, and so I emailed him a calling card number which he could use to call my cell phone. When we finally connected on my cell phone we had the previously mentioned introduction conversation about my research. After trying to figure out how we were going to meet in person, he planned to meet with me during his three day visit to Vancouver for a conference. He offered to connect me with other youth that he had worked with who might be interested in being interviewed, and he went out of his way doing this. The snowball method continued through him, putting me in touch with three more people. He contacted them, and with my permission used my calling card.

Unfortunately none of these interviews ended up taking place. After many emails and

⁶ Kevin Armstrong, AFN HIV/AIDS Coordinator, passed away suddenly in June, 2005. He was an energetic youth advocate and his youth group is now working out plans to establish a scholarship in his name.

phone conversations, one youth became too busy with her work to complete the questionnaire form I had emailed her.

All of the youth I interviewed are individuals that I had formerly known through my work at Sunfire, (the Okanagan youth participant I had met at the Sunfire/Healing Our Spirit annual conference). This emphasizes to me the importance of relationships with marginalized youth, and in Indigenous communities. I had already established relationships with the youth I interviewed. They knew who I was and for the most part what to expect from me. All of the youth who I was put in touch with through snowball sampling were youth who I did not know, and none of those interviews ended up taking place.

Initially there did not seem to be challenges in recruiting participants. The five youth that I connected with from Sunfire were quite willing to be involved. Other than the challenge of not having prior relationships with the youth from the snowball method contacts, all of the participants I interviewed were very supportive of this research and went out of their way to be involved and help me out with contacting other youth. One challenge was making our schedules work, but this is always a challenge when trying to arrange formal meetings with any individual. One youth participant who is highly involved in the Indigenous youth community was very difficult to get a hold of and therefore we were unable to arrange a meeting. After many phone conversations with her over several weeks I decided to not follow through with that interview and moved on to recruit other participants.

Another challenge is that some of the youth did not have voice mail or email, and their contact information had changed. One youth that I was very interested in

interviewing was caring for his pregnant girlfriend while also arranging a move to Prince Rupert and so was unable to meet with me.

EQUIPMENT AND INTERVIEWS

I conducted my first two interviews using a small hand held recorder. This was much more difficult to use during transcribing, so for the rest of the interviews I used a mini-disk recorder. The mini-disk was much easier to review the interview and playback. Also it did not require me to flip sides or change cassettes, as it records much like a music cd, in that I was able to have several different “tracks” which represented different places in the interview where we would stop and start again.

I came to the conclusion that in-depth, individual interviews, guided by a semi-structured questionnaire would be the best way to learn the most information from my participants. I considered doing follow-up group interviews, and the youth all seemed quite interested in doing them. Although group interviews may have revealed a little more information from my interviewees, I was quickly given the impression that the reason why several of the youth wanted to do a group interview seemed to be more to reconnect with the group they had lost touch with and to visit rather than discuss my research topic. Although I would have also enjoyed reconnecting with all of the youth and talking about our work together at Sunfire, the timeline for my thesis writing dominated my decision to not do group interviews. Group interviews would have been predominantly socializing, and would have taken a very long time to organize given the transience of many youth. In the individual interviews I was able to retrieve enough of the information I needed to answer the research questions of this study.

PEOPLE

The target population for my participants was Indigenous youth (under 30) who had been HIV/AIDS prevention peer educators in Canada. All of the interviews took place in person, and they all signed the consent form.

Participants had been involved in HIV peer education for between five years to four months. There were three females and three males. Five of the participants identified as either Native, Aboriginal, First Nations or Indigenous, (specifying the Nation they came from) and one participant identified as non-status Cree. Three participants were 18-19 years, two were 23-24, and one was 27.

There were no participants who openly identified as HIV positive or two-spirited⁷. I did not ask them these questions in order to respect their privacy. Understanding Indigenous youth perspectives on effective HIV prevention education is possible without knowing these details. All participants however indicated some connection to being affected by HIV/AIDS or Hepatitis C through immediate or extended family members. (One youth's brother had just the day before been stabbed with a needle by a drugged stranger on the bus. This youth was worried about the brother possibly being infected and was waiting for the test results.)

The oldest youth, Joulene, (who had been working in Indigenous communities for many years,) in her fascinating interview expressed a deep and complex understanding of the contextual realities of health faced by Indigenous communities. The younger

⁷ "Two-spirited" has various meanings to Indigenous peoples. Nowadays the term is commonly used to refer to gay, lesbian or bisexual individuals. Traditionally each Nation had their own ways of constructing and understanding gender identities. The term has had several meanings, including being reincarnated into a different sex; dressing and behaving like the opposite sex; and having both sexes mixed to become a third gender (Goulet, 1996, p. 683-684). These definitions are by no means conclusive and are simply provided here to offer some basic understanding of the history of the term.

interviewees did not use the same theoretical and analytical terminology or express as extensive socio-political-economic connections between Indigenous health and HIV as did Joulene. Their expressions were based more on their personal experiences and opinions. I wondered if these differences in communication were a result of different life experiences, opportunities, educational levels and age, or did they have nothing to do with these rationalizations at all? Regardless, the feedback can be appreciated as perspectives derived directly from lived experience, and based on what feels right and what doesn't, what works and what doesn't for the interviewees.

My discussions with my thesis supervisory committee were that I would interview between eight to 15 youth. We had agreed that I would attempt to interview youth with a cross-section of backgrounds, including being urban, rural, two-spirited, HIV positive, males and females. We also agreed that my own perspective would represent an additional "interview," as I myself have been a peer educator. It was understood that finding people from all of these experiences might pose a challenge to me given that there is such a small community of Indigenous youth HIV peer educators, and that in working with youth transience, it can be difficult to connect with them given continuous changes in their contact information. After consulting with my supervisor about having completed five interviews it was suggested that I attempt to do one or two more interviews and that should be sufficient for a sample group.

LIMITATIONS

My research was limited by the small sample group I had to work with, which resulted in my only interviewing six participants. Interviewing more peer educators might have

provided deeper insight into the differences in perspectives and needs between rural and urban youth, two-spirited, HIV positive and female and male youth. Further research should focus on gender specific peer education needs and peer educator experiences, as well as homophobia concerns and how these have an impact on the low number of male peer educators.

LOCATION

Two interviews took place at the same Starbucks coffee shop in Burnaby. There was a lot of background noise on the recordings, but as the interview occurred this noise was not as noticeable. I was concerned about privacy for my interviewees and with strangers overhearing our conversation. But the youth did not mind and I think they even felt a little empowered in the sense that someone was interviewing them and it was apparent that they had something important to say. Two interviews took place in family restaurants, one in East Vancouver, and one in North Vancouver. We chose areas where there were no people sitting, so that we had privacy to talk as much and as long as we wanted. One interview took place in a park nearby the participant's workplace in East Vancouver, and another took place at SFU Harbour Centre.

The Harbour Centre was the most uncomfortable location for the interview because it was a space that was out of the environmental context of the relationship that I had built with the interviewee. The interview went well, but the participant, who is usually quite comical, spoke very quietly and both the participant and myself became a little uncomfortable when an older adult sat in the area where we were doing our interview. I would not use Harbour Centre again for this type of interview simply because

it is an academic institution and did not provide the laid back nature of the coffee shops, family restaurant or the park where I conducted the other interviews. These were areas which were either close to where the Sunfire youth project took place, or close to the youth's residences. They were also places that the youth felt comfortable and at ease. For the interview with the participant from out of town, which took place in a family restaurant, there was still the laid back nature of the interview because of it being in a non-threatening, non-institutional environment.

Each of the interviews took approximately one hour to one hour and a half in duration. The time was longer for some interviews due to visiting and catching up after not having seen each other for almost one year. Three interviewees requested to see the transcripts following their interviews. I also emailed each interviewee the quotations that I selected from their interviews and I received their approval to use their wording in this thesis.

CODING

Once my interviews were complete and transcribed I began a process of coding, in order to make sense of all of the raw material I had gathered. With my research question in mind, I read through all of the interviews selecting text that related to my query. I grouped these repeating ideas together, using different colours to identify each participant. These loose categories were labeled by the associated interview question that I had asked. The categories included responses of common interest as well as opposing ideas. I then noticed a sequence of thoughts emerging out of the repeating ideas, so I arranged them into themes. This arrangement allowed me to compare and contrast

perspectives. In considering these themes I was able to organize them into theoretical concepts, while also finding direct quotes. In understanding my themes as concepts, I turned to the literature to see if there existed any relationships between my “theoretical constructs” (Auerback & Silverstein, 2003, p. 39) and other studies. I learned that there existed parallels between what my participants were sharing regarding prevention and peer education and previous research, such as the altruism study discussed in Chapter Two. Fewer studies related my interviewees’ ideas of cultural loss with influencing HIV infection. There was however likeness of this in the study of a non-Indigenous but minority community of Haitian American youth.

CHAPTER FOUR - FINDINGS: VOICES FROM AND TO INDIGENOUS YOUTH

This chapter presents the results of my data collected from personal interviews with six Indigenous youth HIV prevention peer educators. The findings begin by focusing on the participants awareness of HIV prior to their being peer educators. The Fear, Stereotypes and Relationship sections will examine what underlying factors influenced the participants to think certain things about HIV/AIDS. The Impacts of Knowledge section will explore the effects that the interviewees believe being a peer educator has had on them, and will lead into the following sections exploring why the youth chose to stay involved in this work, despite the stereotypes associated with HIV/AIDS, and their thoughts on the unique style of peer education that they delivered, how this affected them personally, and what they hope to see happen in the future.

AWARENESS LEVEL

Three of the six youth had an awareness about HIV prior to becoming peer educators. One youth knew about it from extensive HIV education in his high school on his reserve, and from his father's being infected with Hepatitis C (a virus similar to HIV). Part of Steve's high school education was on reserve where his educational experience was different from in Vancouver. The environment of his school on reserve was entirely Indigenous and the education strove to cater specifically to meet Indigenous students' needs. Previously I discussed how schools, particularly off-reserve non-Indigenous schools, do not meet the needs of Indigenous youth and that is why the limited HIV prevention offered there is not enough to decrease the rising infection rates among

Indigenous youth. The second youth who was aware of HIV prior to being a peer educator was aware of it because he had had a close family member disclose their status to him. Prior to those disclosures, their understandings of HIV was similar to the rest of the youth who became educated during the Sunfire project. Their responses all were that they “didn’t know much about it.” The third youth did not disclose having any immediate connection to a PHA (Person Living with HIV or AIDS) but stated that her mother works in social justice in Vancouver: “My mom talked to me about it. She educated me as to what it is and how you can get it and you know all those things, but I never realized how big it is” (Jessica, personal communication [p.c.], March, 2005). All of the youth, including Jessica, stated that they were scared of HIV prior to learning about it. Jessica became more informed after being a peer educator. Respondents who said that their peers who are educated on HIV do see it as a reality in society, but continue to think they are somehow immune. “I think they acknowledge that it does exist. But they think it can never happen to them” (Jake, personal communication [p.c.], March, 2005). So they see it as a social reality, but not a personal possible reality requiring them to adjust their behaviours.

Jessica continued saying “It’s not in the news. It’s not in the papers. I think some people have forgotten about it” (Jessica, p.c., March, 2005). What stood out as more disheartening is that some of their peers think “there’s a cure” (Jessica, p.c., March, 2005). With all of the youth not realizing “how big it is” (Jessica, p.c., March, 2005) they also stated that they thought “it can’t happen to them, sort of invincible” (Justin, personal communication [p.c.], March, 2005) and “as long as I’m on the pill that’s all I’ve got to

worry about” (Joulene, personal communication [p.c.], January, 2005) when describing how they thought previously, and how their peers continue to think.

FEAR

One youth mentioned that “thank god some of them are still scared of it” (Jake, p.c., March, 2005). I think what Jake meant when he said this is that if youth are afraid of HIV then at least they’re still *thinking* about it and possibly taking some precautions. This issue of fear however raises a concern for me, about whether having youth be *afraid* of HIV is actually beneficial. If youth are afraid of HIV because they realize it is something “big” (Joulene, p.c., January, 2005 & Jessica, p.c., March, 2005) but “don’t even know that much,” (Mikala, personal communication [p.c.], January, 2005) then this ignorance can actually put them at risk. Ignorance and fear about HIV, and how it is transmitted, is directly correlated (in interviewee responses) to stereotypes about who contracts the virus. With young people being afraid of HIV, interviewees say their peers think that only certain members of the population can get it, that “if you’ve got it, you’re automatically dead” (Justin, p.c., March, 2005) and, “that just by looking at someone they could figure out that that person has HIV” (Joulene, p.c., January, 2005). If many youth have this incorrect information, then they may be less concerned about using condoms or sharing drug paraphernalia⁸ or needles (for tattoos, piercings, acupuncture) if their partner doesn’t fit the stereotype. It is more effective for young people to have knowledge and be empowered, rather than simply be afraid. Some youth who are afraid have expressed “I’m not having sex no more! No more, that’s it” (Ott et al., 2003, p. 168). Although

⁸ Drug paraphernalia includes spoons, straws, mixing dishes, filters, swabs, ties, crack pipes, water, dollar bills and paper (YouthCO AIDS Society website, 2005, Transmission Equation section).

abstinence eliminates the chances of becoming infected through sex, it is unrealistic for young people today, and also is a false sense of safety, since sex is not the only way that a person can become infected. “So much of the misconception is based in the fear. Once they understand it’s okay to share a drink, it’s okay to give someone a hug or have them come to a feast, or a powwow or to a sweat. People really look at someone who is living with HIV with different lenses on” (Joulene, p.c., January, 2005).

STEREOTYPES

All of the interviewees mentioned that their peers have stereotypes about who can become infected. The stereotypes are that only “gay guys can get it” (Justin, p.c., March, 2005) and “people that have a lot of sexual partners or else the people that party a lot that are usually potheads” (Steve, personal communication [p.c.], March, 2005), and that young people “still see it as a Downtown Eastside thing” (Joulene, p.c., January, 2005).

By constructing stereotypes such as those above about persons who are HIV positive, people distance themselves from the person they are stereotyping and condemn the stereotyped person as “abnormal.” As a result of the harsh stereotypes, “AIDS is... linked to social and sexual deviance in ways that leprosy and cancer are not” (Stanley, 1999, p. 105). The perceptions of abnormality and “social and sexual deviance” lead to incredibly misconstrued accounts such as, “it’s gay people, monkey... guys who do monkeys I guess and spread it” (Justin, p.c., March, 2005). This process of stereotyping has individuals believing that because they are removed from what they have constructed as “abnormal” behaviours that they are therefore immune from becoming infected. Fewer precautions could possibly then be taken when engaging in potentially transmissible

activities. “A society that chooses to make a running joke of its victims embalms both its conscience and its obligations, relegating a tragic [situation] to ersatz mythology” (Hirschfelder, Molin, Wakim, 1999, p. vii). By creating stereotypes society avoids taking responsibility for its part in the infection process. Social participation in and perpetuation of HIV infection has to do with the socio-political and economic discrepancies discussed throughout this thesis (pages 29, 31-32, 38, 54 and 60).

Stereotypes are created because of racism, prejudice and ignorance, and are one of the major roadblocks in preventing HIV infection. They allow us to avoid our social responsibility towards curtailing social injustices and oppression. Stereotypes about infectious diseases also put each of us at greater risk by giving us a false impression that if we are not “gay” or “partying a lot” on the “Downtown Eastside” then we are safe and do not have to take precautions.

RELATIONSHIPS

As discussed above, three of the interviewees knew someone close to them who was infected with the virus and that is how they became more knowledgeable. Knowing a PHA seemed to have a large impact on all of the interviewees. Their strong responses reflect the impression this had on them.

“It didn’t really become a reality until I had a cousin of mine disclose her status and that kind of woke me up” (Joulene, p.c., January, 2005).

Jake thought it was “only something that’s way out there in the big cities or whatever until it actually impacted my family” (Jake, p.c., March, 2005).

“Yeah [youth see it as a reality if] they know people who have it... they know more than [they did] before” (Mikala, p.c., January, 2005).

“It has totally shifted my whole perspective on life. Everything. Because having someone close to me... because my cousin was someone who had babysat me, I was quite close with, I had seen her go through this transition of ending up in the Downtown Eastside, disclosing her status to the family, and just really connecting ...just because of her infection, that didn’t change who she was. And I think at that age it really shifted how I looked at people in general” (Joulene, p.c., January, 2005).

IMPACTS OF KNOWLEDGE

Gaining knowledge on HIV/AIDS seemed to inspire the participants to become more active in their HIV prevention work. When asked “how do you think your work changed your thoughts and your actions,” Jessica replied “...it makes me want to get more involved” (p.c., March, 2005), and Joulene explained how “once things shifted for me [once she gained knowledge on HIV], I wanted to be connected more around social services all of that” (p.c., January, 2005).

The process of becoming educated on a topic that you were once afraid of, and then of becoming trusted as competent to educate other people about that topic, is

empowering and self-esteem building. “It taught me more on how to teach others. I’m able to explain it to others more properly” (Steve, p.c., March, 2005).

Some youth took it upon themselves to continue their peer education outside of their formal role as presenters in their HIV program. I remember one youth from Sunfire who told me that she would give out condoms to the girls who would work the street on her block at Fraser and Broadway in Vancouver. She said that the women would tell her that if it wasn’t for the condoms she would give them that they wouldn’t have any at all. They also liked that she would give them coloured and flavoured condoms because clients were more willing to use them if they were different. I think this is an important point for HIV prevention in safer sex. The type of condoms that were available was a recurring issue during my work at Sunfire. (This topic did not come up during the interviews, possibly because it did not directly relate to any of the questions.) During Sunfire, youth of both genders would often comment that they did not like or use the standard condoms that were available for free at most community and youth drop-in centres. Because of this feedback we ordered various coloured condoms which came in several flavours. These condoms went like “hot-cakes,” and because these brands cost more I asked the youth if they actually used them or just fooled around with them. They said they did use them and also saved them and gave them to friends.

With regards to peer educators initiating their own peer education outside of the professional setting, Mikala shared the following: “I teach my brothers back home to use condoms... I used to carry around a whole bunch of condoms with me and give them to all my friends” (p.c., January, 2005). I believe that the reason she no longer carries

condoms with her to hand out is because Sunfire has now closed and the peer educators do not directly have access to free condoms.

On the basis of personal conversations that I've had with the peer educators, they have lost some of their feelings of responsibility for educating their peers about HIV, since they no longer have an official role as a peer educator. As a former peer educator myself, I experience some of these same sentiments, such as no longer handing out condoms to friends and youth I run into and no longer having an official "educator" role – but yet still carrying the knowledge and sharing it when the opportunity presents itself. (In the situation of being an educator, having an official role validates and supports people to go above and beyond.) Jessica also discussed handing out condoms to her peers; "I would go to the club. I would pack my purse full of condoms and me and my friends would go give them out. (laughs) I probably stopped one person from getting AIDS [*sic*] that night" (p.c., March, 2005). Justin also said that he would spread the knowledge of HIV transmission even outside of his Sunfire peer educator role. "If someone is wondering I can explain it to them. If someone asked me before about that [before joining Sunfire], I'd just be, 'no I don't know anything'. And now I'd explain it to them, try and help them understand" (Justin, p.c., March, 2005).

Along with the youth's responses of their desire to become more involved by educating others, they also shared how this work had affected their own actions. "I'm completely aware now with partners and things" (Joulene, p.c., January, 2005). Steve replied that:

It'd make me think more before doing something, like if I wanted to have sex without a condom and I really wanted to, it would make me think more of what the risks are. I guess it's more knowing the person and if you feel that you have a really strong relationship with that other person, that kind of falls into it too. It makes me think twice as much even more about doing things basically. (p.c., March, 2005)

He says he didn't change much during the Sunfire project because he had already learned about HIV prior to the project (through his school and father). Even though Steve already knew about the transmission risks with HIV, the significance of the Sunfire project and his role as a peer educator was still meaningful to him. All of the youth, including Steve, mentioned the need for continuity of HIV education. This shows that they feel having constant reminders and continued exposure to information encourages them to stay as safe as they can be.

Jake described a conversation with his mother and how it left an impression with him:

I still drink ...not too much. But when I do I always keep it in my mind to protect myself. I remember it's like three years ago, my mum she had a book saying ways to get infected. In one of them was alcohol. I said 'you can't get infected by alcohol' and she said 'well it affects your judgment'. And then ever since that day I really took that seriously. So when I drink, I always remember that day 'okay even though I'm drunk' ...not to act stupid or anything. (p.c., March, 2005)

One youth discussed her actions towards making safer choices. Jessica said that when she went to the tattoo parlor to inquire about getting her tongue pierced she “checked it out first” (p.c., March, 2005). Mikala expressed that she thinks she’s the same as before in regards to my question of her being “empowered” by the knowledge she gained (p.c., January, 2005). She laughingly said that she’s always been the more controlling one in her year long relationship and indicated that if she wants him to use a condom then he has no choice. She continued to say though “but I think for some women that would be like, yeah” they would have to learn to empower themselves and be stronger (Mikala, p.c., January, 2005). Justin also said that his actions had stayed the same in regards to his own choices on protection. “I’ve always been careful. I know most about it” (Justin, p.c., March, 2005). He also says that “now I understand that you can’t tell that someone has anything by looking at them. I guess it’s just made me more careful” (Justin, p.c., March, 2005). In reviewing his transcripts I note that although Justin says he’s always been careful, he also says that prior to joining Sunfire he

didn’t really know anything about it. I remember [when he had just joined Sunfire] they were asking, ‘what do you know about HIV and AIDS?’” After listing all the stereotypes that he had, “then after weeks they wrote all our ideas (on the board), they crossed out all the stuff that was fake and the truth stood out. Then I was like ‘oh I don’t really know anything’ so I decided to learn more. (p.c., March, 2005)

The contradiction of Justin saying he's always been careful, but yet didn't really know anything about HIV transmission, is explained in his comment: "I've always been careful. It's just cause of that pregnancy thing. I don't want a kid right now. Not until I'm financially ready" (p.c., March, 2005). He was using protection for fear of pregnancy, which means if his partner was on the pill he could still be at risk if a condom was not used.

GETTING INVOLVED STAYING INVOLVED

Recruiting and retaining young people in youth projects can be a challenging task. It can also be one of the defining areas on whether a project's funding is maintained. In researching the issue of peer youth education I felt it was important to understand the reasoning the youth had in choosing to initially become involved, and then to stay involved in the project.

Mikala and Justin said that they went to the first meeting because of the "20 bucks" they were told they would receive for attending. Joulene became involved through her job, as the services she was providing gradually shifted to become more focused on the HIV concerns of her clients. She then applied for a full time job directly related to HIV/AIDS. Jake became involved because the issue of HIV was important to him, due to his mother's HIV positive status, and he also felt inspired at the opportunity to work on his public speaking fears. Most of the youth mentioned public speaking at some point, but only Jake mentioned it as an *initial* reason to become involved. Along the same lines as Jake's on working on what he felt were his weaknesses, Jessica talked about wanting "to help educate myself further to be able to actually understand" (p.c., March, 2005). She's

a very passionate young woman who expressed “I think it was just me wanting to do everything. (laughs) I just want to see everything and do everything” (Jessica, p.c., March, 2005). She went on to confirm that for whatever issue she was involved in she wanted it to be with young people. “I definitely want to start from where I’m at...like it feels more comfortable when it’s at that [youth] level” (p.c., March, 2005). Steve became involved “basically so I can help others. It’s just always been really about educate others” (p.c., March, 2005). He went on to clarify how he’s interested in educating people on social concerns for youth, such as “suicide, drugs and alcohol for example” (Steve, p.c., March, 2005).

All of the youth (except Joulene) became involved because a friend, and occasionally a family member, had encouraged them to attend the first meeting about being a peer educator. Joulene became involved through her employment, and was impacted when, during her employment, a family member disclosed her status to her. This connection personalized HIV/AIDS for Joulene, as knowing a PHA has a deeper impact upon people regarding their knowledge and involvement.

Public speaking, being in front of a crowd, and teaching are themes that were brought up at various points throughout the interviews by each participant. While Jake became involved for the opportunity to improve his public speaking, the rest of the interviewees developed an interest in this after their involvement in the youth project began. “I was all shy, but [for] my first presentation ever [the coordinator] just threw me out there. As soon as we went up, we were all shaking. [I was thinking] ‘what are they going to think?’ But it turned out good.” (Justin, p.c., March, 2005). Mikala continued in the same vein. When I asked her if “other Native youth would be interested in doing peer

education,” she responded “My friends...they are too shy to go up in front of crowds and stuff. But I was shy too and then I did it” (Mikala, p.c., January, 2005).

Each interviewee went on to say that they enjoyed being involved in peer education despite their initial shyness. “It was fun” and “I liked it” came up a lot, as well as their emphasis on the meetings and work being “cool” and coolness being the reason they chose to stay. All of the youth commented on the personal sense of fulfillment that they received from teaching and they directly related this to the potential outcome of making change. When the youth spoke of their passion for making a difference, they often would refer to issues of social justice. Though not having described these sentiments so articulately (except for Joulene), the youth were all drawn towards concerns created by marginalization, exploitation, oppression and inequality. In conveying their passion for making a difference, all of the interviewees (again, except for Joulene) expressed this through their descriptions of how each aspect made them *feel*. Joulene, having an academic, as well as personal, understanding of the sociological context of “making a difference,” related this ‘difference making’ interest to challenging colonization and neo-colonization. She was able to contextualize HIV/AIDS by explaining the history of residential schools, how racism, economic depravity and political subjugation are interconnected with social behaviours and infectious diseases. Joulene’s interview was both an objective *and* subjective description and analysis of why the work that educators do is so fundamental and necessary. Both forms of communication are valid, important and extremely useful in understanding all of the youth’s views as peer educators.

The interviewees' feedback on why they became involved in HIV prevention was holistic in that they tied together education with helping to bring about change. I separated their responses into two areas, 1. the love of educating, and 2. making a difference:

Love of educating: "I love teaching, so I feel right at home being in front of a crowd and sharing information and sharing knowledge" (Joulene, p.c., January, 2005). "It makes me feel good because I educate other people and stuff... Then at the end, you get feedback ...it makes you feel really good inside" (Justin, p.c., March, 2005).

[It made me feel] really good. It was kind of invigorating cause of like... you know I've never really worked in my life or done anything and that was like kind of the first step into it for me and to see what is this all about, right 'do I really want to do this, is this something?' And what I want to do is work with youth so it was just very invigorating. It felt so good when I was doing it (Jessica, p.c., March, 2005).

Making a difference: "it's kind of cool like maybe you're preventing HIV and AIDS" (Jessica, p.c., March, 2005). "I'm making a difference in the Aboriginal community" (Joulene, p.c., January, 2005). "It makes me feel better as a person that I'm helping, helping out something so epidemic and big" (Justin, p.c., March, 2005).

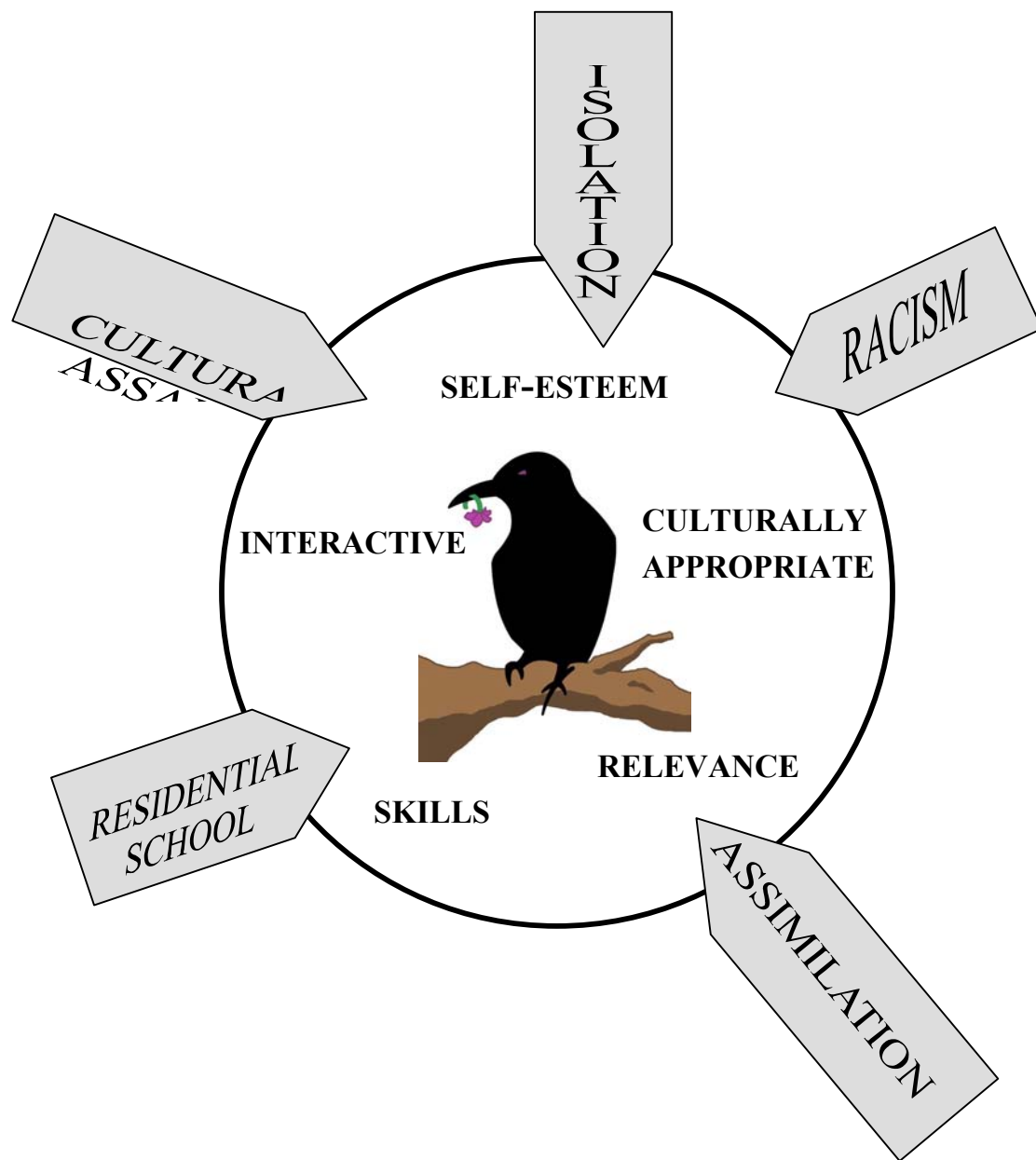
CULTURE AND HIV/AIDS INTERVENTIONS

Five strength building factors emerged from my conversations with the interviewees about Indigenous culture and teachings integrated with HIV prevention. The interviewees associated these factors with young people being able to make healthier choices. These factors are: 1. building self-esteem, 2. relevance of teachings, 3. culturally appropriate teachings, 4. the need for building skills, and 5. interactive learning. (Number two, “relevance of teachings” and number three, “culturally appropriate teachings” are interrelated but not identical. When I write “relevance of teachings” I am referring to making teachings Indigenous inclusive, as opposed to the generic teachings that habitually exclude Indigenous perspectives. When I put forward “culturally appropriate teachings” I mean ensuring that the Indigenous teachings identify which Nation they are from, instead of being pan-Indigenous.)

Five factors also emerged as threats to the freedom to make healthy choices. These are: 1. racism, 2. residential school connections, 3. assimilation, 4. cultural assault, and 5. isolation.

Figure 1: “Strengths and Threats Affecting Indigenous Youth Health” below presents a visual of these interconnected factors. These will be explored throughout the discussion in this section and the following sections “Presentation Suggestions,” “Peer Education,” “Personal Outcomes,” “Recruitment,” and “Continuity.”

FIGURE 1: Strengths and Threats Affecting Indigenous Youth Health



The conversations with the participants regarding cultural teachings in HIV/AIDS prevention were very revealing. All of the youth felt that the presentations that they were involved in were relevant for Indigenous youth. The presentations at Sunfire involved Indigenous teachings throughout, such as the making of medicine pouches or using Indigenous related stories, such as meeting guys or girls at a powwow. The presentations were also developed and presented by Indigenous youth. The reason the interviewees felt the presentations were relevant to Indigenous youth varied. Jessica thought they were “good” because “we did little medicine bags with condoms in them” (p.c., March, 2005), whereas Mikala felt the presentations were relevant because,

HIV and AIDS, isn't it like there's more ... of it in the native community. And they don't really get taught because, I guess our parents are kind of like, oh they don't want to talk about that kind of stuff. ... Youth come and talk to them like other native youth and they'll probably believe us. (p.c., January, 2005)

These responses relate to identity being significant and the need for it to be validated. Jessica's response speaks of cultural teachings, and Mikala's speaks of Indigenous youth relating to Indigenous youth. The five former Sunfire peer educators all mentioned the cultural content in their teachings as being indispensable. They said that the presentations were more interesting that way, and “pretty cool... it also teaches them more about their culture” (Mikala, p.c., January, 2005). Joulene expressed what she has seen as the results of teaching cultural content in her workshops. She spoke of “self-esteem and self-worth” being built and the “sense of pride” that her participants gain

when they learn something new about their culture, and specifically how that connects to their health and protection against HIV (Joulene, p.c., January, 2005).

Joulene spoke of residential school, foster care, adoptions and the 60's scoop as all related to the high infection rate among Indigenous peoples today.

It's all part of the contact, colonization right, not having that sense of identity for someone... if they don't have that connection to that part of their identity, you get low self-esteem. You get involved in addiction, all sorts of things right and that increases the risk for HIV infections. For Aboriginal young females and males ...if they don't have that self-esteem, that self-worth ...they'd be more willing to say 'okay well, maybe we cannot use a condom this time, but next time make sure', right. So I think that said as an educator really saying to youth, you know 'you have a right to say no and have your best interests spoken for.' (Joulene, p.c., January, 2005)

In discussing the importance of learning culture and building identity, Joulene discussed skills that need to be built up in young people who are disconnected from their identity. She explains that communication skills are established by having access to role models and a secure sense of self. Joulene pointed out that Indigenous women who live in remote areas can be in situations of higher risk, due to low self-esteem combined with isolation. As an Indigenous female educator she is a role model and can therefore share her similar experiences. This helps decrease the sense of segregation and feeling that she has noticed

many women experience, of thinking they are the only ones who have experienced certain things.

The females they go, ‘really so you have those stories too?’ They feel more of a connection, right. It probably gives them a sense of relief and a space to feel safe enough to release whatever part of their story they need to at the times (Joulene, p.c., January, 2005).

My discussion with Joulene continued on about why culturally-relevant HIV prevention is needed for Indigenous youth. Joulene related how learning and knowing one’s teachings is related to self-esteem. Identity for Indigenous peoples is connected to a land base, and cultural way of life is connected to that land base. I was surprised when another interviewee brought up the subject of language, when he had previously been saying that HIV teachings should not be different for Indigenous or non-Indigenous youths. He then expressed how he was motivated by two factors:

Where I’m from our language is dying and the rate of our people getting infected seems to be increasing, so that’s also those two kind of interrelate with each other. ...I just want lots of people to stop doing the high risk stuff. I actually want to do that and save our language. (Jake, p.c., March, 2005)

Jake directly related language loss with increasing HIV infection rates, just as Joulene had related a loss of cultural connectedness with high risk choices and increasing

infection rates. These two interviewees directly related language loss to the increase in infectious disease in Indigenous communities.

This brings me to the argument raised by both Joulene and Jessica regarding cultural appropriateness when it comes to Indigenous teachings.

You know we're on the West Coast and how we are taught is you know when you are on someone's territory, you do what they do, right... my daughter goes to school and they have an Aboriginal school. And they would say okay well this is what you are. You need to make this button blanket right, and she's not that.

That's not her. We bead and they are different (Jessica, p.c., March, 2005).

Joulene expanded on this point by adding another dynamic. "Right now, it is a blanketed culture that we are using in a sense. We're acknowledging the diversity but we're not using things that are completely appropriate for you know specific territories we may be entering" (p.c., January, 2005). Both interviewees made the point that Indigenous identity is not being reached and validated in the right way. When Indigenous cultures are being included it tends to be a pan-Indigenous culture. Jessica sees this happening in her daughter's schooling. Joulene is working on how to make teachings more culturally appropriate in her presentations. The issues that arose from the interviewees out of this question of "how to address Indigenous cultural diversity through cultural content in workshops" are:

1. how to make the workshops relevant to both Indigenous and non-Indigenous audience members (because workshops tend to be mixed),

2. how to make workshops relevant to the diversity that exists among Indigenous audience members, and
3. how to respect the culture of the people on who's territory the workshop is taking place.

These are areas that require further exploration in the field of Indigenous HIV prevention. The interviewees answered question number one above. When I asked the interviewees if they felt their workshops were relevant to the Indigenous youth in their audience they frequently told me that their audiences were mixed and were not all Indigenous. Therefore I asked them what they thought of including Indigenous teachings in their workshops with non-Indigenous youth. Their responses often were that the teachings should be kept in.

It's a sense of sharing who we are to kind of bridge some of those gaps and for sharing some of the history so people can have a better understanding and be more empathetic and say 'okay I understand how come [Indigenous people are] facing these conditions and the reason behind them.' Because I think for many non-Aboriginal people, they've kind of taken it for granted and just said 'that's the way it always has been and that's the way it's going to be,' but again it gives them some background information, kind of opens their eyes. At the same time [when] you are trying to explain some of these things and they are coming from a very privileged background and they can't connect completely with those struggles at all. (Joulene, p.c., January, 2005)

I think it basically should be the same except maybe just like... if we do teach it to people who aren't native youth, the native way, it would be kind of cool because they'd be exposed to a different culture. (Mikala, p.c., January, 2005)

I think they would probably listen, but then they would decide on their own whether this is for them or not... I think it really depends on individuals. (Jessica, p.c., March, 2005)

Justin and Steve had similar views to Jessica on Indigenous teachings being included with non-Indigenous audience members. Justin began by saying that "you just try and stick to whatever cultural group and make it understanding for them" (p.c., March, 2005). But then he continued saying that "I think it's good for all ...depends who's in the crowd as long as they understand what you're saying" (Justin, p.c., March, 2005). The point that each interviewee made over and over was the importance of making presentations youth-friendly, cool and funny.

PRESENTATION SUGGESTIONS FROM YOUTH PEER EDUCATORS

In reviewing and analyzing the interviews, a list of presentation suggestions surfaced from the participants. The suggestion that stood out the most, because it was repeated by all of the Sunfire youth, was regarding giving presentations at AIDS conferences where everyone in the audience is already involved in HIV/AIDS in some way. The youth prefer to be as informed as possible about their audience makeup. For example, if the

audience consists of doctors and nurses who are well versed in HIV/AIDS, or if it consists of young people who know very little about the disease, the youth presenters will take a different approach. “I remember that one presentation at that AIDS conference, how the heck do you sit in front of a whole bunch of people that are so educated [about AIDS] and try to teach them about it you know?” (Jessica, p.c., March, 2005). Mikala expressed being “scared” during this situation and Justin agreed, saying it was “kind of hard” (p.c., January, 2005). “The first time we felt so stupid, but the second time it went good. We’re like, ‘just pretend you don’t know nothing’” (Mikala, p.c., January, 2005). The youth presenters were innovative in recognizing the predicament that they were in, and took on a role of acting, pretending the audience were not “doctors and nurses,” as Mikala told me. Jake, who was not a member of Sunfire, but had delivered HIV prevention with other organizations, said

It seems like there’s a big difference between conference workshops and community workshops. It seems like everybody at conferences, they are all already educated. So I don’t feel as good when I’m [presenting] there. You know the messaging ain’t really being sent out. I prefer to plan workshops for people who aren’t educated or need to know more about the topic. So if people teach them, that makes me feel better. (p.c., March, 2005)

Here emerges the first presentation suggestion from the interviewees, as articulated by Jessica regarding this situation. “If I would have known what was coming, then it definitely could have [been] way more prepared” (Jessica, p.c., March, 2005).

Youth presenters need as much information as possible on the backgrounds of their audience, i.e. if they're presenting at a conference to professionals in the field, or to people who have little understanding of the topic. The more information youth are given prior to presenting, the more effective the outcome of their presentation will be, and the more their self-esteem will be nurtured. Young people also want their work and efforts to be worthwhile. They are doing this work in order to make a difference, and in knowing the potential makeup of their audience, the more they can prepare as to what kind of effect they can make. The list of presentation tips continues with a variety of aspects related to HIV prevention peer-led presentations.

Mikala's (p.c., January, 2005) suggestions are:

- The presentations need “to be fun and not boring, or else we'll just lose their attention pretty quickly.”
- If presenters are new they need to have the opportunity for practicing and rehearsing, otherwise “we just forget stuff and we repeat ourselves sometimes and it's kind of embarrassing.”
- “[Guest] speakers are really fun to have.” Occasionally the presentations will include an HIV positive guest speaker. As discussed in the section above on Relationships, knowing a PHA has a large impact on the response of the learner to HIV prevention. For a youth audience, having a young PHA speaker brings the issue closer to home.
- “...and games.” While teaching HIV 101 this section of the presentation can be very dry and boring if not presented with games and humour.

Interactivity is also more of an Indigenous approach to learning and teaching.

- “Usually people when we go to reserves and stuff they know more [culture] than we do. They kind of teach us too.” Here Mikala raises the point that although the presenters may have more knowledge on HIV transmission and they are presenting it in a culturally relevant way, it is important to be unassuming and inclusive of the audience, recognizing that the audience can be involved in the teaching as well. In empowering the audience to share their knowledge (such as culture) educators enhance the learning process overall. Furthermore, this supports the purpose of peer education, to reach the audience on their level.

When organizations involve youth peer educators who are volunteers, often they’ll only make time to call the youth to come in for the delivery of the presentation. This doesn’t take into account the reality and experience of the youth peer educator, who feels as much responsibility as the staff. Mikala’s suggestions emphasize the importance of ensuring that youth peer educators are involved or aware of the behind the scenes organization of their workshop.

Suggestions raised by Justin (p.c., March, 2005) are:

- Using flash cards. “It worked way better.” He’s suggesting flash cards to use as notes that they (presenters) can refer to in guiding their presentation.

- “The condom demonstrations. I love those.” He’s speaking of HIV 101 and when he and his workshop partner would wear bath robes and teach the youth how to put on a condom. “Everyone was dressed all business type and we come with our robes. I enjoyed that.” They used a lot of humour in this presentation, and Justin and his partner were named the “Condom Boys” in Indigenous and non-Indigenous youth magazines across Canada.
- He also refers to the importance of knowing the most recent information on transmission. “...cause it’s always changing right.”

Jake expressed the importance of discussing alcohol as a strong risk factor. “I want to elaborate more on that during the workshop. I think I wanna just make my next workshop just go over HIV/AIDS 101 really quickly.... [and then focus on how drinking leads to risk]” (Jake, p.c., March, 2005). His point is extremely important, as alcohol is a common activity that youth engage in together. It is also something that puts young people at risk of spreading HIV (and other infectious diseases or infections) because when people are intoxicated they rarely think of using protection or safer practices.

Joulene emphasized the need for “more interaction. You retain so much more of the information when involved in an activity” (p.c., January, 2005). She discussed how it’s more appropriate for Indigenous learners: “I don’t think for many Aboriginal communities, a lot of their teaching wasn’t done while we were sitting down and being lectured to” (Joulene, p.c., January, 2005). She explained how she found it more effective to have her audience members participating during her presentations.

Along the lines of interactivity and involvement of the audience, Joulene referred to cultural appropriateness as being essential. She explained how this can be achieved in relation to HIV prevention:

You would have to have somebody from the inside [community] and joining and teaming together where I would hopefully, eventually give them all the information, train them in the components of HIV then that would be the piece from within the community they would have someone take that on and say, ‘okay I’ve got the culture, I’ve got the songs, I’ve got the teaching and I’m going to apply it to the new information I’m learning about HIV.’ But at first we have to join together as a team and cross-section that information together. (Joulene, p.c., January, 2005)

Joulene says that having the workshops conducted in Indigenous languages is another hope that she has for Indigenous communities, and this is another way to bring in culture into the presentations. The youth “are really thirsty for wanting to know their language. It’s all about connection, identity for them” (Joulene, p.c., January, 2005) Since I completed the interviews I have learned that Healing Our Spirit has begun to conduct prevention workshops in Indigenous languages, starting with the Carrier Nation.

Joulene spoke of the importance of researching how to join together with communities, by speaking with Elders from various Nations. She says it’s important to find out how to make the teachings relevant when going into different communities, each with a different culture and language:

Cause right now, it is a blanketed culture that we are using in a sense. We're acknowledging the diversity but we're not using things that are completely appropriate for specific territories we may be entering. So I'm really wanting to make sure that component's in there so that if I'm entering into Nisga'a territory, I would follow their protocol and procedures. I think it's vital, I think that's the only way we're going to make progress in regards to this. (Joulene, p.c., January, 2005)

YOUTH VIEWS ON PEER EDUCATION

In discussing peer education with the interviewees, we discussed this as both youth-to-youth as well as Indigenous-to-Indigenous work. I asked the interviewees how they felt in their experience as audience members when they were being presented to by adults as compared to by someone their own age. All of the interviewees agreed that they would pay more attention if they were being spoken to by someone their own age, particularly about sex and drug topics. "Well kind of feels a little uncomfortable when you have like an old person talking to you about sexual activity and all that, (laughs). It's just an awkward feeling" (Steve, p.c., March, 2005). Steve went on to say that young people his own age would relate more to his lifestyle, and that he would receive this information from an adult as a lecture. He said that if it was a youth it would be more like hearing a friend talk to you. Jessica said peer education is "like eye-to-eye" (p.c., March, 2005), and Jake stated that "it gives a stronger message" (p.c., March, 2005).

Regarding Indigenous-to-Indigenous education, the intensity of their answers varied. All interviewees said that it would be effective to have Indigenous peer educators, but some found this more important than others. My understanding of the reasons for some youth's indecision about the importance of Indigenous educators is that being taught by primarily non-Indigenous educators is their norm. To be taught by Indigenous educators is a newer occurrence that not so many students have experienced in school or other formal settings. Many youth hunger for cultural teachings and Indigenous mentors, but in the interview responses they more readily connected cultural teachings and Indigenous mentors with something accessed outside of the school setting. The responses to having Indigenous educators versus non-Indigenous educators has to be based more on a hypothetical situation as opposed to having concrete experience to compare and contrast. Steve was one of the interviewees who was indecisive about how important this was, but still he went on to say... "I guess you'd feel more comfortable teaching to Native youth I guess and they'd probably feel more comfortable that you're Native" (Steve, p.c., March, 2005).

Further on the topic of Indigenous peer educators, three interviewees mentioned the differences between youth from the reserve and urban Indigenous youth. "The city Aboriginal youth" (Mikala, p.c., January, 2005) were referred to by Jessica as having more of a connection to the "street" (Jessica, p.c., March, 2005), and by Mikala as knowing more about sex than youth from reserves. She expressed this because of her experience of these topics being "forbidden or whatever to talk about sex with young kids. And youth out here [the city] they get taught all the time in schools and everything" (Mikala, p.c., January, 2005). Therefore some of the youth's wavering on the necessity of

Indigenous educators could be because talking about sex on reserves and in Indigenous formal settings is less common than in non-Indigenous schools.

It is useful to note however that Steve's experience seems to contrast that of Mikala's. Steve mentioned that most of his knowledge of HIV/AIDS came from living on his reserve where he received many presentations. However, the specific topic of *Indigenous* presenters was not mentioned when he talked about learning about HIV/AIDS on reserve. Steve said that if the presenter was non-Indigenous and therefore "didn't know about a reserve, they wouldn't be able to answer a question. I guess it would be more hard for them to answer. The reserve is totally different from the city for example. There is different traditions, different ways. So yeah, you would feel more comfortable [being presented to by an Indigenous peer educator]" (Steve, p.c., March, 2005).

Joulene was one of the interviewees who saw a serious need for Indigenous peer educators:

It's so necessary for the youth to have someone that they can connect to and identify to [so they can] feel safe with the person that's presenting to them. I find more with the youth than the adults when I acknowledge that I'm Carrier and that I'm from Burns Lake and I acknowledge who my family is and many of the youth right away figure it out and say 'oh, do you know so and so, do you know so and so...oh you must be related to me. You must be my cousin.' And you can see it, it lightens them up, they have a sense of connection with you. It's a part of their identity that makes a world of difference for them. It's

vital to have that, I think so and it's something that needs to be sustainable and ongoing for them. (p.c., January, 2005)

This connection and affirmation of identity for the audience by the peer educator is an effective and necessary part of truly and deeply reaching your audience.

PERSONAL OUTCOMES OF BEING A PEER EDUCATOR

For young people, and particularly youth who are marginalized and face risks, to take on the role of being a peer educator is one that helps build confidence, security and self-esteem. In order to speak to an audience of young people who are at high risk of potentially contracting HIV, it is important to involve members of their peer group in delivering the message to them. As was discussed in my literature review, this practice has a double benefit; it not only serves to more directly reach the young people to whom the message is being sent, but it also serves to provide education and opportunities to the peer educators themselves.

All of the youth peer educators had positive feedback on their involvement in peer education. The responses included the work being “fun,” “invigorating,” “makes me feel good” and the pride they felt in teaching others. When I asked them if anything moved them about their work, the feedback that stood out the most was when Jessica said that seeing young male peer educators was most inspiring to her. There are many more young women who work as peer educators as compared to young men. For the men who were involved they were strongly dedicated to the work. “I felt empowered to see the young guys there and to see that they're wanting to get educated... I find a lot of young guys

nowadays....There's no respect you know... and to see those guys sitting there was really awesome" (Jessica, p.c., March, 2005).

RECRUITMENT

An important aspect of prevention education is how to recruit and maintain peer educators. I felt this was an important question to ask my interviewees because they are the ones who did much of the recruitment for the project. The youth weren't assigned to recruit other youth but rather did so out of their desire and support for the project.

Above I mentioned that there are more females than males in Indigenous youth HIV/AIDS peer education. I asked the youth their perspectives on this and the females had more to say about this than the males. Jessica thinks that "girls are way more open to talking about sexuality than guys are at such a young age" (p.c., March, 2005) whereas with young men she thinks guys make fun of each other and there's more pressure from their peers to look cool. Joulene laughingly said,

We love talking. It's something we are more comfortable with... I think it's maybe in part cause our society that's what they are expecting is to be taught by their women, but who knows. I think it's mostly cause we know how to talk.

We've got the skills. We are brought up that way. (p.c., January, 2005)

Justin said that he thinks males might be "scared, cause they would be stereotyped as gay" (p.c., March, 2005). It is evident that a lot of work needs to be done in order to come to a place where we as a society, and as an Indigenous community, can talk openly and

comfortably about HIV/AIDS without the fears of the associated stereotypes silencing our conversations.

When I asked the interviewees for specific suggestions on how to recruit youth, their feedback most often referred to making it known that the project is fun and cool. Joulene emphasized “having more cultural relevance” in order to reach Indigenous youth (p.c., January, 2005). Jessica thinks that a good point for recruitment would be to let young people know that “there’s this place where you can go if you want to learn and be able to be involved” (p.c., March, 2005). Mikala suggests recruiting youth who are “loud” (p.c., January, 2005). However this was not the case for many of the youth interviewed. From my experience as the coordinator of Sunfire, I found that recruiting youth for the purposes of joining a youth-run project was enticing. Avoiding pressuring youth to become presenters early on allowed their confidence and comfort levels to be built up. Once they saw that other youth were giving presentations in teams, they gradually became interested in presenting themselves. The youth in Sunfire were also involved in the decision-making of the project. Although there were paid staff who made the final decisions, the feedback from the youth members was always taken into consideration.

Joulene and I had a conversation about young people becoming interested and remaining involved in the project. She felt this was because of the “shift we’re seeing in our communities” where youth “are becoming more educated and understanding about oppression, about racism, and all of those things. They are saying ‘hey wait a minute I don’t have to stand up to this anymore. We can make a difference, we can create some change’” (Joulene, p.c., January, 2005). During this conversation with Joulene I went on

to say that “with HIV, [youth] are wanting to be presenters on HIV and maybe it’s because in our workshops we’re showing, ‘hey it’s not only about HIV, this is connected to everything’.”

CONTINUITY

At the end of each interview I would ask each youth if there was anything that they wanted to add. To my surprise every interviewee referred in their own way to the need for continuity of projects like Sunfire. Jake prevention workshops and that “you have to keep reminding people” (p.c., March, 2005), it can’t just be a one time thing. Joulene explained how when she enters a community and does an HIV prevention workshop there is a community development worker from her organization who attends that same community a week or so after to assist the community in establishing their own ongoing prevention program. According to Joulene, her workplace (Healing Our Spirit) is the only Indigenous organization in BC that is focused on setting up ongoing prevention programs. She says that there is not enough funding allocated for the community development worker to keep up with the prevention workshops that she delivers, and communities are suffering because of this disparity.

That I can really attest to, to needing more educators, definitely and that there needs to be more programs ...there’s at the most four educators within our province that do this work amongst 198 Aboriginal communities and that’s just on reserve, regardless of the urban centers. It’s phenomenal that many of us

stick around as long as we do because of burnout and stress. So it's amazing. So there's still gaps that need to be filled in. (Joulene, p.c., January, 2005)

The youth that I interviewed were very passionate about the need for more projects like Sunfire. The project offered them work experience, a healthy social environment, community networking, education about safe lifestyle practices and leadership experience. I recall one youth from Sunfire (who was not interviewed due to schedule conflicts) having told me that one of the reasons she was involved in so many Indigenous youth projects was because they kept her busy and away from partying. The more youth meetings she had to go to, the less time she had to party. Sunfire also provided the young people with the health building factors discussed earlier in the "Culture and HIV/AIDS Interventions" section of this chapter. These are self-esteem building experiences, relevant teachings, opportunities for culturally appropriate teachings, skills building experiences and a dynamic interactive environment.

CHAPTER FIVE – DISCUSSION AND RECOMMENDATIONS

FINDING MY PLACE

Working with youth in an area affecting social justice and educating others about their health and safety is something that reaches you deep inside. I have worked as an educator and coordinator of many projects dealing with social concerns. HIV is an area that has impacted me and stayed with me profoundly. Although my academic and employment paths began as being very political, my heart was always in youth work. My passion has always been to empower youth to have their voices heard.

I grew up experiencing various difficulties and challenges and because of these my voice and feelings were often invalidated and ignored. This turned into a strong belief in the power of validation and the need for voices to be heard and feelings expressed. This conviction is what influenced my choice to shift my academics from political science and Indigenous Governance. Education and curriculum development is a place where I felt I could have more of a grassroots impact upon marginalized youth's experiences and opportunities, while still incorporating my political background. I believe that every young person has the ability to learn, and has the right to learn in ways that work for each of them. In seeking methods that work for young people to learn effectively, youth voices need to be included in learning and teaching processes. My goal with my academics and career path was to involve youth in the process of curriculum development and learning and teaching. Interviewing youth about their experiences as HIV prevention peer educators is a part of the process of validating youth voices and involving them in the development of their education.

FINDING SUPPORT

Many of my interview findings were supported in the literature I reviewed. The literature on HIV prevention projects (except the altruism study) discussed the socio-economic unrest faced by the communities in discussion. The altruism study did not focus on any one cultural community and therefore did not discuss infection rates of various populations and the correlated social contexts. The Haitian youth's study referred to the need to address cultural loss and to incorporate traditional health customs practiced by members of the community because, "developmental factors, including...cultural and ethnic identity issues may enhance adolescents' propensity for HIV risk behavior" (Malow et al., 2004, p. 130). All of the youth interviewees from my research talked about Indigenous cultural teachings as necessary HIV infection interventions. "The communal nature of Aboriginal healing is in marked contrast to the more circumspect practices of biomedicine" (Waldram, 1997: 103). The literature by Waldram et al. identified Indigenous medical practices and this coincides with my findings on why cultural relevance is important.

The Wang and Keats article's discussion on physical isolation in parts of China resonated with my findings on remoteness. "Everything [HIV education services,] seems to be centralized in the main city like Vancouver for us. [It's important to have] something up North, something in the Interior so that you can get more of the communities involved and get them starting and doing something within their own community" (p.c., January, 2005). Other participants discussed the differences in thinking about sex and HIV/AIDS in rural reserve communities. All of the HIV

prevention literature reviewed in this dissertation made reference to the need to target stereotypes. My findings revealed that the same stereotypes are still common in Indigenous youth communities. However, to have a more clear analysis on the frequency of stereotypes in the Indigenous community it would be necessary to interview youth who are not connected to HIV prevention. Most of the participants of this study had been involved in prevention for quite some time, and so any misperceptions they had had were clearly reduced. Their responses to questions about stereotypes were retrospective as to how they perceived HIV years before, and were second hand when referring to how their peers comprehend HIV.

The significance of peer education was a central finding to the interviews and was supported by the literature in terms of same-sex-to-same-sex, youth-to-youth, and cultural-group-to-cultural-group. Unique educational approaches such as interactive learning, humour, guest speakers and storytelling were also consistent in both the literature and interviews. The Wang and Keats (2005) study, the altruism study (2003) and my findings referred to participants of the prevention project being empowered by their roles as educators. The altruism study and my interviewees spoke of their identities as educators and the sense of responsibility they held.

FINDING SURPRISE

There are particular findings from my interviews that stood out to me which were not addressed in the literature. These findings offer pertinent information for the field of HIV prevention with Indigenous youth. It is hopeful however that these findings also provide

value to populations beyond the Indigenous community in Canada, as the findings of the Roma, China and Haitian-American studies have informed my research in such a way.

My interviews included discussions around the prevalence of female as opposed to male youth as Indigenous HIV peer educators. From my recollections of attending peer education meetings at YouthCO AIDS Society (which is non-Indigenous specific) in 2004 there seemed to be more females there as well. However this is not conclusive and is simply based on my observations at a few meetings. The risks faced by Indigenous women compared to men did not come up directly in my interviews, although there are some very real differences. The focus of my interviews was to discuss prevention according to the experiences of the participants, all of whom had participated in coed prevention workshops. During pre-contact periods gender relations varied from community to community, but in many cases women's and men's concerns were considered interrelated. It is frequently acknowledged today within Indigenous circles that what affects one individual affects the entire community. European influences of unequal gender roles have impacted Indigenous communities over time; nevertheless traditional views are still known and recognized. Perhaps the lack of division between gender concerns in my interviewees' responses is partially a result of a communal-oriented epistemology. I was surprised at Jessica's response to my question about what inspired her about the workshops. She immediately referred to the "young guys... wanting to get educated" (Jessica, p.c., March, 2005) about safer sex. There appeared to be no discomfort from my interviewees with males having been involved in discussions about sex and drugs with mostly female youth.

Another finding that grabbed my attention was Jake's mention of alcohol as a contributor to HIV infection. We were so deep into an emotional discussion about how HIV had affected his life (through his mother's being HIV-positive) that infection through the use of alcohol was not immediately on my mind. Common associations of HIV infection are intravenous drug use and sexual transmission, so Jake highlighted an important and often overlooked risk behaviour. Jake went on to surprise and impress me even further when he brought up the need for language revitalization and how that could contribute to lessening the AIDS crisis in Indigenous communities. Gregory Cajete (1999) highlights why: "The idea of a culturally-based approach to...education for Native Americans is a new development...and reflects an evolution of thought related to self-determination, community education and a renaissance of Native American identity" (p. 26). Joulene also made reference to the importance of language revitalization. Wang and Keats (2005) discussed language but only as a means of communicating the prevention strategy appropriately. They found that "language suitability was high" (p. 886) and "culturally appropriate expression [used] local idiom in ethnic community languages" (p. 881). The languages of the communities involved in the prevention did not face language threats, so the use of "appropriate" language was not connected to reviving cultural connectedness.

Discussion around relationships was an integral part of every aspect of this research. The interviewees indicated the importance of relationships in discussing youth-to-youth education, (that it would be more friend-like,) and culture-to-culture, (that they could relate better). This stresses the need to build relationships with the workshop participants. My interviewees said that they became involved in HIV prevention because

of a friend or family member and recruitment of more peer educators at Sunfire was most often through relationships of the current peers. My interview recruitment was impacted by relationships as I had previously known each participant. The recommendations by the youth were that having an HIV-positive guest speaker made a large impression.

Relationships were not directly discussed in any of the literature. The literature that can be interpreted as acknowledging relationships are the discussions on the educators building relationships with their peers and same sex discussions in Roma communities. The final surprising interview finding was a strong emphasis by each interviewee on the continuity of the teachings and the need for follow up by a community development worker to create preventative outlets and resources for communities.

CYCLICAL FINDINGS

In looking at the themes which emerged from my findings in a different way I see deeper interconnections between them. The 12 themes can be condensed into three groups because of their connected dynamics. I have identified the groups as “Learning,” “Knowing” and “Teaching.” Metaphorically these groups represent the phases of the child, the adult and the elder, because learning and growing are cyclical. See Figure 2 below for a visual of the groupings and phases.

My examination of the themes revealed that “Awareness Level,” “Stereotypes,” “Fear” and “Relationships” are connected. They represent components of a child’s development and learning processes including: the possible learning of misleading information (from friends or media, for example,) becoming afraid, developing

meaningful relationships and beginning to gain a more complete understanding. For these reasons I have termed the grouping “Learning.”

The second phase is adulthood and the grouping is “Knowing.” As individuals gain information they are “impacted by that knowledge;” there is action that habitually follows inspiration, which represents the “Getting Involved Staying Involved” theme. Then adults are able to assess their “views” on their actions and recognize which “outcomes” are for them.

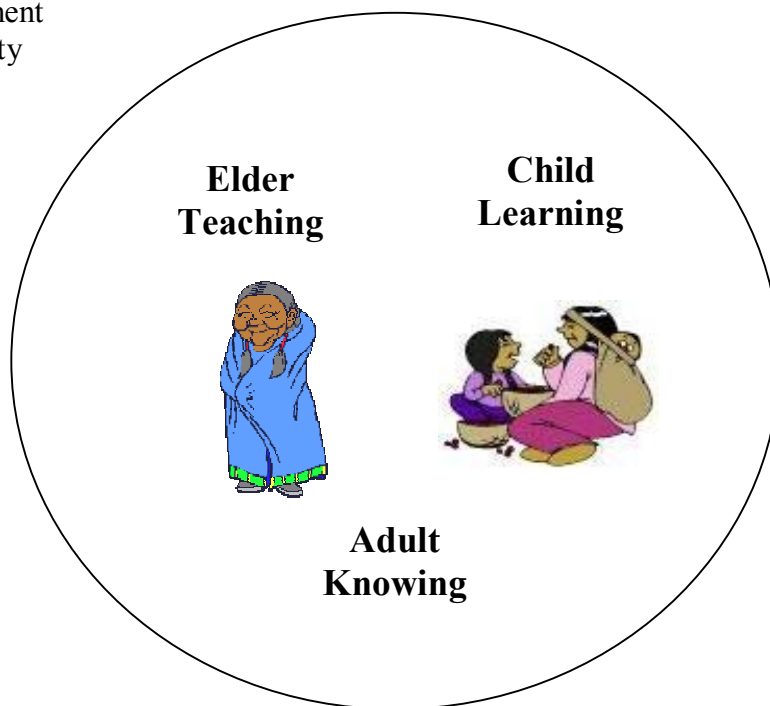
From an Indigenous perspective Elders are considered teachers, hence the grouping “Teaching.” An elder would have an understanding of “culture” and “interventions” or processes that have worked and that have not. Teaching includes recognizing and incorporating effective teaching methods (“presentation suggestions,”) being able to “recruit” listeners and recognizing that the learning process is “continuous” and cyclical.

The youth peer educators’ experiences, as shared in their interviews, reveal that each one of them went through the learning, knowing and teaching phases. They experienced a developmental journey which is metaphorically expressed as passing through childhood, onwards to adulthood, to being an elder.

FIGURE 2: Finding Phases

TEACHING

- ⌘ Culture and HIV/AIDS Interventions
- ⌘ Presentation Suggestions from Youth Peer Educators
- ⌘ Recruitment
- ⌘ Continuity



LEARNING

- ⌘ Awareness Level
- ⌘ Stereotypes
- ⌘ Fear
- ⌘ Relationships

KNOWING

- ⌘ Personal Outcomes of Being a Peer Educator
- ⌘ Impacts of Knowledge
- ⌘ Getting Involved Staying Involved
- ⌘ Youth Views on Peer Education

FINDING RECOMMENDATIONS

The six participants in this study were supportive of my research and were very open about how infectious disease has affected them personally, and how it has influenced their involvement in peer education. They were all willing to discuss their views on youth perspectives about risk behaviours, and their varying levels of awareness about HIV/AIDS. I interviewed the participants at an appropriate time, because the prevention project that four of them were involved in had closed within a year, and so their passion and interest in the work was still lingering. The objective of my research was to understand Indigenous youth peer educators' views about the HIV prevention work they had delivered. The results from the data reveal that all of the interviewees agreed that peer education is the most effective way to prevent HIV infection with young people; that recent colonial history and Indigenous cultural connectedness is associated with health outcomes; that AIDS-related stereotypes need to be reduced; the importance of nurturing relationships; how to create constructive peer education; and, the necessity of continuity.

The research presented in this paper exposes the diverse perspectives of Indigenous youth as they pertain to HIV/AIDS and health. Particularly of note is the youth's emphasis on cultural appropriateness. This means the appropriate cultural content that is specific to each Indigenous Nation and each Indigenous person's cultural identity. Also, each one of the participants, to my surprise, concluded their interview by emphasizing the need for continuity of teachings in order for the messages to be preserved and adhered to, and for more projects like Sunfire to take effect.

Each participant in my study, including myself, are at different places in our relationships with our cultures, in understanding the importance of identity, and in

distinguishing the impacts of colonial history. As the youth have indicated, all of these areas play out in health related decision making. Every interviewee's position is equally valid, as they reflect the varying realities and perspectives of young Indigenous individuals. Ideas about advantageous HIV intervention techniques also varied. Some of these involve the need for Indigenous language inclusion, more cultural content, more of a focus on how alcohol is a risk for infection, and making the programs cool, "fun and not boring." Two of the strongest features that the youth recommended for prevention education were the inclusion of an HIV positive guest speaker (who is appealing to a youth audience) and the use of humour.

Relationships in an Indigenous context are invaluable. Strong kinship and clan relationships were how communities operated prior to contact, and how they continue to function, in the face of colonial intrusion. Prior to contact, each person had a role and responsibility in community sustenance, and their relationships with the rest of the community ensured that every person was interdependent upon one another. The importance of relationships that emanated from my research involve the needs of youth to connect with someone who is HIV positive, to have a connection with their culture as they learn about their health, to have youth to youth relationships for peer support, and to have each of these be continuous. These relationships are substantially interrelated with understandings of oneself and having a strong self-esteem. Therefore, nourishing these relationships in HIV prevention education can have a deep impact upon increasing identity and self-esteem, and decreasing the infection rates of young Indigenous people.

This area of research specifically addressing Indigenous culture and HIV prevention is relatively new. It is important for more research to be conducted on the

connections between Indigenous identity and HIV infection. Research required includes a look at the relationship between HIV infection and Indigenous cultural disconnection, foster care and interracial adoption.

Indigenous organizations must continue to be funded to provide ongoing HIV prevention education to youth, and mainstream schooling should incorporate my findings on how to meet the needs of Indigenous youth. Prevention of infectious diseases in mainstream schooling should include diverse cultural content, and become obligatory subject matter. “Significant learning is directly related to the degree of personal relevance the student perceives in the educational material being presented. The basis for such a premise stems from the idea that motivation toward any pursuit is energized by one’s own constellation of personal and socio-cultural values” (Cajete, 1999, p. 88). Within teacher training courses, Indigenous Elders and youth can be brought in to talk about Indigenous ways of learning and teaching, and the importance of cultural inclusiveness. In order to have better outcomes with Indigenous students and participants, educators should incorporate peer knowledge, cultural perspectives, humour, and build dynamic and interactive learning environments.

“Young [Indigenous] persons, whose lives seem so full of promise, [can be] so tragically and disproportionately prone to acts of self-destruction” (Chandler & Lalonde, 1998, p. 214). Youth who face higher risks must be given opportunities to be young leaders, such as peer educators. Altruism is a motivating factor for young people, particularly when they have rarely had a strong sense of being helpful to others, and have instead often been perceived as troublesome youth. Culturally relevant opportunities need to be created for Indigenous youth to become peer leaders.

This thesis has presented youth's views primarily on HIV prevention programs offered through Indigenous organizations, but Indigenous inclusive health education can and should also be delivered through non-Indigenous health organizations and public school curriculum development. HIV prevention education can only be wholly effective if it is supported from all realms of education impacting the lives of youth. Public school teachers, youth workers, youth service providers and Indigenous organizations all have got to take part in ensuring Indigenous relevant content is included. This will participate in revitalizing Indigenous cultures, nourishing youth identities, and decreasing the number of risks that are happening in the Indigenous youth community. This information is intended to assist educators of all kinds around the needs of Indigenous youth. The recommendations in this study can be applied to youth education on a variety of subjects beyond the realm of HIV prevention.

A CALL TO ACTION: DETERMINATION TO SAVE LIVES

Historically, “serious illness [in many Indigenous communities] was viewed as a penalty for a prior transgression of the moral order. ...Confessions by individuals, detailing breaches of the order that they had committed in the past, was an essential ingredient of treatment” (Waldram et al., 1997, p. 100). The *Gathering Strength's Statement of Reconciliation* (delivered in 1998) was a step in the right direction by the Canadian government in confessing prior “breaches of the moral order” (Waldram et al., 1997, p. 100).⁹ Funding of \$350 million was committed by the Canadian government to create “a

⁹ *Gathering Strength* was the Canadian government's response to the 1996 Royal Commission on Aboriginal Peoples report. The response was “a long-term, broad-based policy approach designed to increase the quality of life of Aboriginal people and to promote self-sufficiency” (Indian & Northern

healing strategy to address the legacy of physical and sexual abuse in the Residential School system” (Indian & Northern Affairs Canada [INAC], 1998, Introduction section). The Aboriginal Healing Foundation (AHF) was created to administer these funds. The funding was to be distributed within a certain timeline which has now (2006) been reached. Organizations have suffered from these cuts, but the thousands of individuals who experience characteristics of the “syndrome” (as discussed on pages 20-21) have suffered the most. Indigenous individuals who were in a process of healing, developing and repairing their skills were cut off from their resources, from 2004 onwards. There are discussions of new funding agreements but none to the extent of the original commitment. Not only did I see clients at Healing our Spirit BC Aboriginal HIV/AIDS Society cut off from service provision (due to AHF funding termination in 2004), but I myself was a client at an organization funded by the AHF when their funding terminated.

In meeting the “essential ingredient of treatment” (Waldram et al., 1997, p. 100) to repair transgressions of the “moral order,” the Canadian government must continue to fund programs for healing of residential school, language revitalization and cultural rehabilitation. There need not be a funding time limit placed on the healing process of repairing over 500 years of colonial abuses and oppression. However, the question arises: how can “reconciliation” and holistic healing take place when the abuses are still ongoing? As discussed throughout this paper, Indigenous peoples are still facing media stereotypes, land theft and displacement, the imposition of status and the ongoing effects of residential schooling. The reality is still one that “if you are an Aboriginal person

Affairs Canada [INAC], 2004, Canada's Aboriginal Action Plan section). The *Statement of Reconciliation* acknowledged “the mistakes and injustices of the past” (INAC, 1997, Foreword section).

living in British Columbia, your standard of living is likely to be 20 per cent below the provincial average” (Provincial Health Officer, 2002, p. 1).

A more holistic solution to repairing the damage done by the Canadian colonial state is for Canada to support the implementation of Indigenous self-determination. As Chandler and Lalonde assert, “communities that have taken active steps to preserve and rehabilitate their own cultures are shown to be those in which youth suicide rates are dramatically lower” (Chandler & Lalonde, 1998, p. 192).¹⁰ If self-determination is not supported within Canadian society it is imperative that Indigenous communities “wrench” (Chandler & Lalonde, 1998, p. 209) control over their communities out of the hands of the Canadian state. If for no other reason than to save the lives of the disproportionate number of Indigenous youth who are committing suicide at a rate three to five times higher than non-Indigenous peoples (Chandler & Lalonde, 1998, p. 201), and who are becoming infected with HIV at a rate of “roughly 10% higher than youth infections in the non-Aboriginal population” (Canadian Aboriginal AIDS Network, 2004, p. 1).

This research is instrumental in bringing forward the voices of Indigenous youth about their concerns on their health and their recommendations on how to improve their standards of living. The intended implications are to dramatically **advance peer education** and **Indigenous youth involvement** in the teaching that they receive so as to improve the health conditions of Indigenous youth in Canada.

¹⁰ “Culture,” according to the Chandler and Lalonde study, includes governance over community affairs and land-base.

This is a passionate call for **base-budget funding** of harm reduction, HIV/AIDS and Hepatitis C prevention specific to Indigenous youth, in a manner that directly incorporates cultural revitalization.

A CULTURAL METAPHOR FOR MY FINDINGS

The preservation and rehabilitation of culture is not so intimidating a feat as might be perceived, but it certainly has to be catapulted ahead. I was once told a beautiful metaphor about the perception of cultural loss.

Culture is like a stream, it runs underground and you forget that it's there. Every now and then it appears above ground and you can see it, taste it, hear it and touch it. When the stream is running underground it is important to always remember that it's there and it hasn't disappeared. Like culture, it is important to always remember that it is there and can be brought back to the surface. Sometimes you can see it, taste it and hear it, but there are many parts that one needs to remember to feel. Culture is not always tangible and also represents a way of seeing, perceiving and responding to the world. Indigenous stories and histories are encapsulated in the land. One need only remember how to listen.

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APPENDIX 1

Core elements of the popular opinion leader (POL) model

1. Intervention is directed to an identifiable target population in well-defined community venues and where the population's size can be estimated.
 2. Ethnographic techniques are systematically used to identify segments of the target population and to identify those persons who are most popular, well-liked, and trusted by others in each population segment.
 3. Over the life of the programme, 15% of the target population size found in intervention venues are trained as POLs.
 4. The programme teaches POLs skills for initiating HIV risk reduction messages to friends and acquaintances during everyday conversations.
 5. The training programme teaches POLs characteristics of effective behaviour change communication messages targeting risk-related attitudes, norms, intentions, and self-efficacy. In conversations, POLs personally endorse the benefits of safer behaviour and recommend practical steps needed to implement change.
 6. Groups of POLs meeting together weekly in sessions that use instruction, facilitator modeling, and extensive role play exercises to help POLs refine their skills and gain confidence in delivering effective HIV prevention messages to others. Groups are small enough to provide extensive practice opportunities for all POLs to shape their communication skills and create comfort in delivering conversational messages.
 7. POL's set goals to engage in risk reduction conversations with friends and acquaintances in the target population between weekly sessions.
 8. POL's conversational outcomes are reviewed, discussed, and reinforced at subsequent training sessions.
 9. LOGOs, symbols, or other devices are used as 'conversation starters' between POLs and others.
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Source: Kelly, J. A. (2004). Popular opinion leaders and HIV prevention peer education: resolving discrepant findings, and implications for the development of effective community programmes. *AIDS CARE*, 16(2). Page 141.

APPENDIX 2

Interview Questions

1. What do your peers think of HIV/AIDS and who gets it or can get it?
2. Do you think they see it as a reality in their worlds? How and why, or why not?
3. How and what did you think of HIV/AIDS before getting involved in prevention education?
4. How and what do you think of it now?
5. Do you feel that anything influenced you to change your behaviours and be safer with sex, drugs or needles (piercings/tattoos)? Like did being a peer educator for example influence you?
6. What do you think of the work that you do as a peer educator on HIV/AIDS issues?
7. How does it make you feel to do it? Why?
8. Do you think it makes a difference? How or why, or why not?
9. Do you feel and think that the presentations are relevant for Native youth? How and why, or why not?
10. What else could work regarding involving Native teachings in HIV/AIDS prevention?
Like learning about things that we never had the opportunity to learn...
Like the importance of coming of age ceremonies...
Why we always need to make responsible healthy choices?
Any others that you can think of?
11. Do you think the presentations could be better? How and why, or why not?
12. What do you like and dislike about the presentations that you've done?
13. What more can be done to make them even more appealing for Native youth?
14. As a youth yourself, have you noticed any changes with your friends who you talk to about HIV prevention, or with youth that you've given your presentation to? What kinds of things have you noticed? Any changes in their behaviours?
15. Do you think HIV prevention should be different for Native youth than for non-Native youth? Why or why not? If so, what kind of things can be done, or what would you like to see done more, or changed?

16. How and why did you get involved in HIV prevention?
17. How does it make you feel to do it?
18. Have you felt empowered or have your actions changed in relationships because of the knowledge you've gained?
19. Are there changes you would like to see, or ideas that you'd like to suggest?
20. Do you think that other Native youth might be interested in doing peer prevention education? Why or why not?
21. Is there anything else that you would like to add that I have not asked you about?

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