First Nation Perspectives on Why First Nation Youth Are At Risk for Hepatitis C

by

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ABSTRACT

The prevalence of Hepatitis C (HCV) in the First Nation youth population is unknown, however, it is understood that the rate for HCV in First Nation people is 7% higher compared to the non-First Nation population. HCV is contracted via blood to blood contact through activities such as sharing syringes, crack pipes, tattoo and piercing equipment with someone infected with HCV. In this qualitative study, ethnography research methodology and a community-based research philosophy were used to examine why First Nation youth are at risk for HCV within the 13 – 17-year-old age group and what recommendations they offer health care providers and First Nation youth on the prevention of HCV. The sample included fifteen First Nation youth as well as eight Elders participating in a focus group that sought to elicit advice ranging from what questions to ask Youths to participants’ suggestions on prevention of HCV.

Data analysis consisted of in-depth interviews, focus group participation and field notes focused on language used to describe risk-taking, when youth start using drugs and why they risk-take. Prevention ideas were gathered at the same time. Five themes emerged: Surviving risky lives; In search of positive role models; being a First Nation youth means taking risk: living as a member of a culture whose traditions have been eclipsed by violence; access to health care; and awareness of HCV. There is a great divide in how Elders and youth view youth’s role for the future. First Nation people think of Seven Generations ahead of the one they exist in. However, today’s First Nation youth are putting aside their future until a later time in their lives; they define their own current culture of surviving being at risk. The framework used to understand the issues of risk-taking and prevention of HCV is the Braid Theory (Mind, Body and Spirit strands) that I developed out of the need to help others understand why First Nation people do not comply with western medicine regimes.
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CHAPTER ONE: INTRODUCTION

The Learning Stories—As bridges toward understanding, as a way of practicing life without falling over its cliffs, as a way of honing a keen appreciation of the possibilities and of the wholeness within which those possibilities may be identified... the People evolved Three Learning Stories, one for each fundamental aspect of this Life Experience.

One for Body,

One for Mind,

One for Spirit. (Underwood, 1994, p. 67)

Hepatitis C (HCV) has reached epidemic proportions in Vancouver and the Lower Mainland. One of the groups identified as highest risk for HCV is First Nations youth who reside within this region (Miller, La Liberte, Spittal, Li, O'Shaughnessy, & Schechter, 2002). The exact number of affected and infected First Nations youth is not known because of the difficulty tracking HCV in this group. Recently, health promotion advocates have pointed to the need to prevent HCV in First Nations people before they encounter practices that lead to the transmission of the hepatitis virus; i.e., before they are adults (Browne & Fiske, 2002). Unfortunately, many of the prevention strategies that have been used in this population have not been perceived as culturally relevant by First Nations people and few have had sustained effects in the prevention of HCV (Lohrmann, et al., 2000; Task force Report for Health Canada 1997; Tierney 1991). The proposed research addresses some of the limitations of previous efforts to target First Nations youth.

Background to the Problem

I was able to locate only one published research study about HCV in the First Nations youth population. Hepatitis C is a relatively new disease and not yet widely known among the First Nations youth population, although approximately 300,000 Canadians are infected with the Hepatitis C virus (Heathcote, Yim, Quynh, & Sherker). The incidence of HCV in First Nations people is difficult to track because the requisitions used in testing for HCV do not request
ethnicity. The trends in HCV infection are often compared to that of Human Immunodeficiency Virus (HIV). Patrick et al. (2001) reiterate that the study of HCV is parallel with HIV and allows for comparison of incidence trends, risk favors and socio-demographics. Another issue in regards to the incidence of HCV among First Nations people is that First Nations people find it difficult to visit a health care system for testing. Their conceptions of health and health-care often differ from those of health-care providers from whom they seek assistance. Both cultural differences and sociopolitical experiences influence such misunderstandings (Browne & Smye, 2002; Van Uchelen, Brasfield, Davidson, Demerais, & Quresette, 1997). First Nations people often fear and/or experience discrimination directed at racial minorities and marginalized subgroups; this frequently inhibits them from approaching health-care facilities staffed by 'mainstream' caregivers (Ship & Norton, 1998). Likewise, fears around lack of confidentiality, security or anonymity inhibit access to testing and prevention programs (2-Spirit of the First Nation, 1996).

First Nations people make up approximately 4% of the population (Calzavara, Bullock, Myers, Marshall, & Cockerill, 1999). Yet in 2001, they represented 17% of the newly diagnosed HIV for the year 2001 (BCCDC HYPERLINK http://www.bccdc.org/HIV/Surveillance System). When Dawar, Buxton, Patrick, Johnson, and Ng (2001) analyzed Vital Statistics and the Public Health Information System (PHIS) data of Status Indians for HCV of British Columbia in 2001, they reported that 10.7% of the data indicated that Status Indians had HCV. Hepatitis C and HIV are contracted similarly (Highleyman, 1999). For example, one way of contracting HCV and HIV is through sharing dirty needles (i.e., tattooing, injection drug use, piercing) with someone infected with the virus (National Association of Friendship Centres, 2002). However, it must be known that HCV is a very low risk for sexual transmission. The Aboriginal Nurses Association of Canada (ANAC, 1997) confirms, "HCV infection is transmitted by sharing drug paraphernalia
for injection drug use (IDU) accounting for about 70% of the 240,000 estimated HCV cases in Canada” (p. 2). Nationally, it is reported that the rate of HCV amongst First Nations people is 7.5 times higher than Non-First Nations population (National Association of Friendship Centres, 2002). Locally, the Vancouver Injection Drug Use Study (VIDUS) investigated 235 youth injectors, of whom 24% were First Nations. Of this sample, 39% were HIV positive, while 82% were HCV positive (Miller, La Liberte, Spittal, Li, O'Shaughnessy, & Schechter, 2002). Miller et al. point out that “First Nations youth were almost 5 times more likely to be HIV positive and almost 4 times more likely to be HCV positive than Non-First Nations youth” (p. 6).

Since HIV/AIDS is contracted similarly to HCV, it is important to keep in mind HIV/AIDS statistics to clarify the need to develop a HCV prevention program for First Nations youth. The Canadian Aboriginal AIDS Network (CAAN, 2002) clearly states, “First Nations AIDS cases are younger than non-First Nations cases, 28.7% of First Nations people who are infected are under the age of 30, compared to 17.6% in the non-First Nations population” (CAAN, pamphlet, p. 2). This confirms that First Nations youth are at high risk for HCV that is; double the risk for contracting HIV. ANAC stresses, “due to the relative 'newness' in identifying HCV as a serious and transmissible infection with a potential to cause great social and financial strain to the health care system” (p. 2), there is a need to bring about awareness of HCV in order for prevention to occur.

All youth are at risk for HCV for many reasons. Brendtro, Brokenleg, and Van Bockern, (1990) claim that our approach to understanding “at-risk” youth must avoid “blaming the child” and instead direct our attention to the environmental factors that need to be addressed. They suggest that youth who are at risk are “alienated,” “troubled” and “difficult” (p. 2). However, they have also identified at-risk youth as courageous yet discouraged. They stipulate that a
program to reduce the health risk of at-risk youth must address courage as the ‘courage to be’ and discouragement as the ‘discouragement with the environment’. It is important therefore to develop a prevention program that would include activities that do not discourage youth from being part of the circle of life while at the same time accentuating their courage.

Purpose of the Study

The ultimate purpose of this study is to describe and explain what constitutes the culturally relevant components (dimensions) essential to an intervention to prevent HCV for First Nation youth. Secondly, it is to describe how First Nation youth become at risk for HCV. This study was conducted in collaboration with Traditional Elders and key informants in the First Nation population. Based on the findings of this study, recommendations for culturally appropriate interventions were developed aimed at preventing HCV among at risk First Nations youth.

Objectives

- To identify culturally relevant principles for the prevention of the transmission of HCV among First Nation youth
- To identify, in collaboration with Elders and key youth informants, an understanding of how to frame the risk factors for HCV that are specific to First Nation youth
- To determine best practices as identified by Elders and key youth informants in preventing the transmission of HCV among First Nation youth
- To make recommendations for interventions to prevent the transmission of HCV among First Nation youth.
Theoretical Framework

The theoretical framework for the proposed research was The Braid Theory (Barney, 1999). I developed this theory out of a need to explain why First Nation people do not comply with Western Medicine, and it has been validated in many presentations to both First Nation and non-First Nations audiences. The roots of the Braid Theory are First Nation oral tradition about the strength of three strands in braided sweet grass or hair. The braid is a metaphor of what is needed to be healthy in the First Nations tradition. The Braid Theory describes the body as holistic, with components of Mind, Body, and Spirit. The theory is applicable to First Nation people of North and South America because it is relevant to how they understand the prevention of disease. The Royal Commission on First Nations People (RCAP, 1996) calls for health professionals to “bring balance and vitality to body, mind, emotions and spirit as ends in themselves and as preconditions for balance and vitality in their societies. In short they are looking for whole health” (p. 7).

The Braid Theory is comprised of three strands: body (physical), mind (mental), and spirit (spiritual). According to First Nation tradition, all three strands are important for the person to be in balance. The RCAP Report (1996) reminds us that “First Nations concepts of health and healing start from the position that all the elements of life and living are interdependent” (p. 9). Therefore, it is also important for these three strands to be intertwined or braided together for when one braids hair or sweet grass, the resulting braid is very strong compared to single strands. This metaphor emerges in human experience, for example, Anderson (2002) found that First Nations youth who become sexually active and/or pregnant at a young age, do so, “out of loneliness and a need for love” (p. 11). Shah (2003) maintains that “Spiritual people are often at peace with themselves or have what is called ‘inner peace’; they feel connected with their fellow
human beings and other creatures in a meaningful and caring way through their practice, beliefs, and values” (p. 17). He reminds us that spirituality is not synonymous with the institutional basis of religion, as its impact on health may manifest in psychological mechanisms that reduce stress. Social support is also a strong buffer for stress (Lazarus & Folkman, 1984).

Accordingly, when in balance, the person is healthy, physically, mentally, and spiritually; this in turn promotes wellness. According to the Braid Theory, when wellness is achieved, the person is responsible for him or herself and respects self and others. Central to application of the Braid Theory is the assumption that the strength of First Nations people is closely tied to their connection with their cultural ways and community. Joseph (RCAP, 1996) explains that in her Nations’ language (Gitksan and Wet’suwet’en) there is no mother tongue word for health. However, they do have a word for strength, which is used to connote health. Well-being is associated with high self-esteem, a feeling of being at peace and being happy. Wellness and well-being can also include satisfaction in education, employment, land claims and resource management (Joseph, RCAP, 1996). Culture is viewed as providing a sense of responsibility and ways of caring for oneself and community (Olson, 2001); similarly, First Nations cultural beliefs and practices appear to fit well within traditional health promotion initiatives. The Ottawa Health Charter defines Health Promotion as follows:

The process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment. Health is, therefore, seen as a resource for everyday life, not the objective of living. Health is a positive concept emphasizing social and personal resources, as well as physical capacities. Therefore, health promotion is not just the responsibility of the health sector, but goes beyond healthy lifestyles to well being. (http://www.ldb.org/vl/top/ottawa.htm. Ottawa Charter on Health, 1996)

The Elders within the First Nations community are believed to hold cultural knowledge that they transmit to others in the community (Davis & Taylor, 2002). Unfortunately, there are
fewer Elders in today's world that have knowledge of traditional ways (Smye & Browne, 2002; Turton, 1997). First Nations scholars are calling for a return to traditional ways and a need for tapping into the knowledge of Elders who hold cultural teachings related to the prevention of illness or promotion of wellness.

The ancient ones taught us that the life of the Tree is the life of the people. If the people wander far away from the protective shadow of the Tree, if they forget to seek the nourishment of its fruit, or if they should turn against the Tree and attempt to destroy it, great sorrow will fall upon the people. Many will become sick at heart. The people will lose their power. They will cease to dream dreams and see vision. Their lives will become filled with anger and gloom. Little by little they will poison themselves and all that they touch (The Four Worlds, 1984). The significance of culture to First Nations people cannot be denied. Psychologist, Michael Chandler was interviewed by Forthsythe, a CBC reporter (November 19, 2001). He spoke on the suicide rate of First Nation youth being three to seven times higher than the non-First Nation community:

Everyone's aware that the First Nations communities of North America, and Canada, and BC have been savaged, if that's not too strong a way of putting it, by having their children removed from their care, their language forbidden, their cultural practices outlawed, and as a consequence of this most First Nations communities are holding on to what's sometimes just the tatters of a 10,000-year-old community. So... many First Nations bands are hard at work to try and reconstruct, or reconstitute, or somehow strengthen their cultural heritage and ties. (Interview, CBC Radio, Michael Chandler and G. Forsythe, November 19, 2001, BC Almanac)

The Braid Theory clarifies how First Nations youth are at risk (discouraged), and shows us where we can focus prevention initiatives (courage), strength, and spiritual ties to the body and mind. For example, a youth who is alienated from his First Nations community is unable to achieve wellness and will seek community among others, particularly youth who share his experience as an alienated person, e.g. street youth. First Nations people may leave home for
many reasons, “to improve their education, look for work or escape family violence. Once in the cities, they can lose family support they depended on at home. If they have troubles, they may find urban services difficult to penetrate, alien in spirit and perhaps racist” (p. 3). The RCAP Report further explains that while many make a successful transition, however, others fall into the cracks between cultures, become isolated; remain unemployed and under-served. This in turn exposes them to unsafe practices, such as sharing needles for drug injection that place them at risk for HCV.

The Braid Theory is used to guide the proposed study because it directs the researcher to look at the physical, mental, and spiritual components related to acquiring or preventing HCV among First Nations youth. The Braid Theory also provides direction in determining the research design (e.g., the interview questions will reflect the components of the framework and assist in the interpretation of the research findings). An example of an interview question founded on the Braid Theory is: “How has your move away from your family and community affected your experience with drugs?”

Significance

The proposed research provides health care providers with direction in the prevention of HCV in First Nations youth. The research approach models ways that First Nation Elders and youth could contribute to HCV research as experts in the knowledge of First Nation and First Nation youth risk prevention. The research also provides answers to why First Nation youth put themselves at risk, or how it is they become at risk. Further, this research may help to prevent the spread of HCV in the First Nation youth population.

The research is also significant because it addresses the need to include First Nation youth and Elders in research about First Nation people. The Natural Sciences and Engineering
Research Council of Canada (NSERC) suggests that “there is growing recognition that some research involving First Nations individuals may also involve the communities or groups to which they belong” (http://www.nserc.ca/programs/ethics/English. Involving First Nations Peoples in Research. Section 6). This is particularly important because, in the past, much research about First Nations people has had negative consequences. Schechter et al (2002) explain that “the historical and continued betrayal characterizing many governmental policies directed at First Nations peoples demands [that] a response to these epidemics come in collaboration and from First Nations communities; otherwise the effects may be minimal” (p. 8).

Organization of the Thesis

In this chapter, I introduced the background to the research, as well as the purpose, objectives, and theoretical framework of the study. In Chapter Two, I explore research-based literature regarding the prevention of transmittable diseases in First Nation youth populations. In addition, I identify how researchers have included traditional Elders in such research. In Chapter Three, I detail the research design, including the data collection, data analysis strategies and rigor. In Chapter Four, I describe the research findings as revealed by the participants, including their recommendations for an intervention to prevent HCV among First Nation youth. In the final Chapter, I explore the implications of the research findings for health program planners, community health nurses, researchers, and the First Nation population.
CHAPTER TWO: LITERATURE REVIEW

Introduction

In this chapter, I review research-based literature regarding interventions to prevent transmittable disease in First Nations people, youth in general, and First Nations youth populations. In addition, I identify ways that traditional Elders have been included in research about the experience of First Nations people. I begin with lessons derived from research and about the evaluation of interventions, specifically those that pertain to the prevention of illness in First Nations people. Then I explore prevention initiatives that involve youth in general. Finally, I identify the outcomes of prevention interventions that are specific to First Nations youth.

Shah (2003) identifies the three different traditional approaches to disease prevention as primary, secondary, and tertiary. Primary prevention is aimed at disease before it occurs; secondary prevention involves early detection of disease, and the treatment that may accompany screening and tertiary prevention is aimed at reducing death and disease through treatment and rehabilitation.

This research focuses on primary prevention, and is directed at developing recommendations to First Nation youth to prevent First Nations youth from taking risks that can lead to HCV (Shah, 2003). The field of research regarding prevention of disease among First Nations people has largely focused on diabetes, cigarette smoking, sexually transmitted diseases (STDs), and HIV/AIDS. Although this is not surprising due to First Nations people's high risk for these diseases, the predisposition of First Nations people for HCV is substantially higher than for HIV/AIDS. The HCV virus is transmitted more easily through blood than HIV, is more potent than HIV and is acquired earlier after the sharing of needles (Wiebe, 2000). Wiebe goes on to state, “Compared to HIV, the Hepatitis C virus is 10 to 15 times more infectious by the
spread of blood” (p. 1). Crofts et al. (1997) and Van Beek et al. (1999), cited in Wiebe (2000), explain that Canada’s “programming for Hepatitis C has consisted of an extension of existing HIV or STD programs . . . As a result of significant differences in the nature of transmission these efforts have not been successful” (p. 1). HIV, STDs, HCV risk factors and transmission are all associated with networking communities, such as First Nation communities; for instance, Calzavara, Bullock, Myers, Marshall, and Cockerill (1999) believe that the selection of partners is not a random activity but one that is determined by the individual’s social network and environment.

There is a paucity of research on the prevention of disease that is specific to First Nation youth. In general, youth's needs are presumed to be addressed in research that includes First Nation people of all ages. However, 30% of First Nation people are under 15 years of age, (Liberal Plan, 1997) a figure that demonstrates a need for a separate intervention program dedicated to First Nation youth. The body of research that deals with prevention of disease in First Nation people is largely quantitative in design, involving extensive survey instruments that are often culturally irrelevant. Two-Spirit people of the First Nation emphasize, “Statistics are human beings with the tears wiped away” (2003). While there is no research specific to the prevention of HCV in First Nation youth, the following section discusses prevention/intervention initiatives that are both targeted toward First Nations people and community-based.

**Development of Prevention Interventions for First Nations People**

In this section, I discuss interventions that have been implemented with First Nations people for the prevention of disease, specifically, how they were developed and evaluated. I also draw upon the identified indicators of success, and summarize researchers' recommendations about how interventions could be most effective for First Nation people. The principal focus in
research on First Nation people’s health is on risk factors; the evidence-based interventions that have been implemented are few (Young, 2003). I was unable to locate specific educational strategies used with First Nations people in the area of prevention of HCV. However, I describe some interventions that have been implemented with First Nations people for other purposes, such as the prevention of diabetes. I also describe the few interventions that have been targeted toward First Nations youth. As in the previous section, I emphasize that most interventions are focused on cognitive outcomes. Many of these are not published in scholarly journals but are available in reports of First Nations organizations and government bodies. I include in my discussion the ways in which Elders have been included and provide examples.

A great deal of intervention research among First Nations people has been directed toward the prevention of diabetes. Many of these studies have been participatory in nature, capitalizing on First Nations people’s desire and need to be actively involved in research decisions. For example, Green and colleagues (1999) used a participatory action approach to design and evaluate an intervention to prevent diabetes among First Nations people in British Columbia. Simmons and Voyle (2003) performed a similar study with 436 Maori people of New Zealand. The researchers claim that the Maori and other Indigenous people across the world experience the same life style as First Nations people, for example, low activity level, obesity, smoking, excessive alcohol consumption, and exhibit high rates of diabetes. They emphasize that conventional approaches to disease prevention are inadequate for such people. They examined a Maori diabetes program that focused on Maori culture and assessed its outcomes in terms of risk behaviors. The researchers concluded that the prevention programming settings that are the most conducive to participation, and in which participants feel the most relaxed and amenable to learning, are community meeting places within familiar social networks.
Although there have been several research studies that have investigated the outcomes of prevention programs among First Nations people, researchers often conclude that these programs are limited in their effectiveness because of cultural irrelevance and lack of First Nation community input in the research design and process. For example, in the analysis of the outcomes of diabetes education programs on Vancouver Island, King-Hooper (1995) reports that they "have often fallen short of their goals when 'transplanted' to Native settings ... the result of communication barriers created when the principles underlying health models lack Native cultural integrity ... The health education and health promotion messages are expressed in terms of non-Native ways of believing, thinking and doing" (p. 20). Johnson (1991), reporting on research about the sweeping epidemic of diabetes in First Nation communities, emphasizes the "importance of involving the Native community in their own health care. Their own beliefs and customs must be considered and incorporated into any diabetes education program, to make it culturally relevant, or culturally sensitive, and ultimately more effective" (p. 15). They and other researchers (Aboriginal Nurses Association of Canada [ANAC], 2001; Wilson & Rosenberg, 2002; Ellerby, 1999; ANAC, 2002; Van Uchelen et al, 1997) stress that the success of a prevention program among First Nations people depends on how the developers attend to the way First Nations people believe, think and act in their daily lives. For example, they recommend that prevention interventions among First Nations people should include the sharing of stories of what works, or what happened when someone shared a dirty needle with another person (Hakim & Wegmann, 2002). King-Hooper et al. (1995) state, "mere lip service to 'cultural sensitivity' [in the development of prevention interventions] is not adequate, nor appreciated by native people" (p. 9). In addition, researchers report that the prevention programs with the highest rates of participant attendance and increases in positive health behaviors are
those that include the direct involvement, support and teachings of Elders and community leaders. Beniot (2003) suggests that Canada’s First Nations people have reasserted control over their health and social services including the design and delivery of programs.

There are a few examples of successful disease prevention intervention programs provided by First Nations organizations. One such example focuses on HIV prevention. It is called the Health is a Community Affair Campaign, referred to locally as the ‘Door-to-Door Project’. Health Canada sponsored this promotion project that focused on STDs and HIV/AIDS prevention among First Nations people (Health Canada, 1993). Community health workers and community members were trained to canvas and deliver HIV/AIDS and STD health information door-to-door (Crown, Duncan, Hurrell, Octoova, Tremblay, & Yazdanmehr, 1993). ‘Plain’ language was used in the information materials; some were in Inuktitut dialects and some were in French and English. This project also utilized other means of transmitting HIV/AIDS information to First Nations communities. Project implementers used community radio stations to inform the community of the campaign; they also displayed posters related to the campaign in public places. Band Chiefs, Council and Elders were always informed about the campaign at its outset. The project implementers notified the Elders first, to gain support before approaching the council (p. S56). They also obtained appropriate support from Chiefs and band councils to promote community ownership of the initiative.

The evaluation of the “Door to Door Project” initially entailed written evaluation forms, but the project implementers soon found that the written questionnaires were of limited effectiveness in obtaining feedback from the public (Crown et al., 1993, p. S57). The community’s oral tradition was strong in comparison to the use of written communication (Commanda, Grey, Kue Young, & Masuzumi, 1999; Crown et al, 1993; Kaufert, 1999). The
campaign was successful because community members came out to the workshops, they heard the messages on the radio, and they now support those with HIV/AIDS and see the importance of preventing HIV/AIDS from spreading in their community. The “Door-to-Door” project paved the way for further health promotion initiatives, particularly the prevention of HCV in Inuktitut communities (Crown et al., 1993).

The Chee Mamuk program (2002), situated at the British Columbia Centre for Disease Control, STD/AIDS Control Division, developed and provided a prevention/awareness initiative that was similar to the Health Canada initiative. I am an employee of the Chee Mamuk program. The idea for a door-to-door campaign came from a brainstorming session with representatives of “Healing Our Spirit” and the First Nations Program at Children’s and Women’s Hospital in 2002. The discussion arose because when we provided workshops in First Nations communities, few people attended. In the past, when a function was happening in First Nations communities, the “door-to-door” approach was effective in communicating the event. People who were invited generally attended the event. However, the door-to-door approach has been abandoned in favour of technology, such as the telephone and the Internet.

Another prevention initiative as presented by Heffernan (1995) is a diabetes project with First Nations people. The project utilized principles of Action Research and community development. The research team sought opinions from the participants from the beginning, and their involvement continued throughout the project. The community members who participated spoke freely as “the Haida tradition is an oral one, and whoever is speaking has the floor until finished; this is a perfect setting for the orderly conduct to productive group discussion” (p. 276). Heffernan observed that even though the members with diabetes learned about their illness (diabetes), they still had difficulty following the regime set out by the biomedical team (diet,
exercise, blood sugar testing). Overall, the researchers viewed this project a success in detecting diabetes and concluded it fostered the feeling of strength and hope. Heffernan notes that social bonds in native communities and willingness to act for the benefit of the group can provide a supportive network, providing a strong foundation for prevention programs.

In summary, the successes of disease prevention programs with First Nations people have been related to their inclusivity with all ages in the First Nations community. In successful programs, First Nations community members were included from the beginning of the planning process of the prevention program to the implementation of the program. The evaluation of the effectiveness of programs required creative approaches that acknowledged the significance of the oral tradition of First Nations people. Another factor that increased the effectiveness of disease prevention programming was using traditional methods of inviting people to events; for example, inviting people to events happening in their community in person. Another of way of viewing success in an intervention program is to accept how First Nations people value language and ways of thinking, for example, to look at the positive side (strength) of a person, as opposed to focusing on illness (weakness). In the following section, I discuss how culture can be integrated into interventional approaches to disease prevention.

Culture in Prevention Programming

France (1997) reports that there is a recent resurgence of interest in First Nations culture among those in the First Nations community and those who work with First Nations people. Stephenson and Elliott (1995) agree. In their preface to A Persistent Spirit: Towards Understanding First Nations Health in British Columbia, they state, "The spirit of First Nations peoples may have waned under the crushing force of colonial oppression, but it is now
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resurgent” (p. iii). The use of First Nation cultural beliefs and values in providing prevention initiatives for and with First Nations people is increasing in appeal.

In the following section, I discuss research initiatives that utilize First Nation cultural beliefs and values as a way of providing prevention services. An example is the study by Van Uchelen et al (1997). This research team investigated mental health among First Nation people in the Downtown Eastside of Vancouver, British Columbia. The researchers concluded that First Nation people see culture as the foundation for wellness. The research participants they interviewed emphasized a holistic view of wellness connecting culture, the earth and spiritual elements. They also highlighted and saw strength in their indigenous resources. Van Uchelen and colleagues suggested that much of the research about First Nation to date “tends to focus on the pathology, needs, and deficits—in essence, what makes people weak” (p. 37). They maintained that First Nations culture can provide resources in health promotion; ultimately the prevention of disease among First Nations people is best achieved if prevention interventions focus on the people’s strengths.

The Aboriginal Nurses Association of Canada (2002), in a discussion paper entitled “Traditional Medicine and Primary Health Care Among Canadian First Nations People,” also call attention to wellness in the context of prevention. The authors of this report state, “Primary Health Care and Traditional Medicine both emphasize the prevention of illness and the promotion of health” (p. 1). They caution that it is not feasible to separate traditional First Nation medicine from First Nation culture. Traditional Medicine encompasses activities and items such as sweat lodges, smudge, prayer, dancing, singing, and drumming. One example they provide to illustrate the assertion that Traditional Medicine includes culture is ‘bad medicine.’ In Traditional Medicine, health is a gift from the Creator and First Nations people are cautioned not...
to betray this gift, or ‘bad medicine’ can occur. Bad medicine occurs when one strays from the gifts given to one, for instance wellness. Therefore, sickness and physical imbalance can be regarded as due to lack of exercise, or poor nutrition; according to ‘bad medicine’ it can also result from negative thoughts or the failure to observe certain cultural values, ways of living, or taboos. Bad medicine can also result when someone harms another person; for example, sexually abusing someone, or demeaning another, resulting in negative energy that can be in the form of a hex or a curse placed on another to imbalance that person’s being, mentally, physically, or spiritually. When bad medicine is practiced on oneself or others, the imbalance between what is culturally reasoned as health and what is unhealthy puts First Nation people at risk for diseases such as HCV. In accordance with Traditional Medicine, therefore, First Nations people who have turned to drugs or alcohol may do so because they are practicing bad medicine.

The Haida Gwaii Diabetes project drew on the help of Elders’ views of traditional foods as being “our medicine” (Heffernan, 1995). At the same time, the project implementers discovered some aspects of traditional feasts as being problematic because feasts traditionally provide food for more people than are present, and no food is to be left behind. Therefore, people take home the foods that are filled with sugars and fats; this puts those with diabetes at risk and presents a risk to those prone to developing diabetes. Heffernan (1995) indicated that a lesson to be learned from this project is that traditional feasts may bring people together; however, a balance of involving traditional practices such as feasts with education requires cautious planning. The Haida Gwaii people viewed disease as contagious, requiring isolation of the ill person from others in the community. The ill person would also take from the stew pot last, being careful not to infect others. Haida Gwaii people also believe that disease comes from “evil spirits.” One is prone to disease if one’s mind is weak and allows the transmission of the disease
to happen. As one of the participants stated, “You believe in something hard enough, it will come so. So, just remember your mind has a lot do with your body” (Heffernan, 1995, p. 281).

Heffernan (1995) observed that the strength of the Haida Gwaii Project was that it focused on the strength of the people and their culture, “physical strength which allowed the wide-ranging travels, the food gathering and trade of the past, strength of mind, which kept disease at bay, spiritual strength which is drawn from the culture and beliefs of the Haida Tradition, and finally, the strength which comes from helping each other” (Heffernan, 1995, p. 282). A community member who is an artist designed the logo of the project after being told of the nature of the project and captured the image of mind, body and spirit (e.g., Raven, Eagle, and Human) in a circular setting with three hands connected to each other representing the different aspects of the project.

In summary, the concept of strength has been central to successful prevention programs among First Nations people. Strength is described as being within each individual, and within groups of people in the community, physically, mentally and spiritually. In the following section, I discuss disease prevention interventions targeted toward youth in general.

**Youth Interventions**

Interventions for disease prevention among youth have been largely focused on preventing HIV and sexually transmitted diseases (STDs), as well as preventing and eliminating substance abuse. Shoveller and Pietrsma, (2002) evaluated the quality of prevention interventions on 289 HIV/AIDS published studies in North America. They also assessed behavior change interventions to prevent HIV/AIDS among people ages 12 - 24 years. Using pre-specified criteria, only 20 of the 289 studies qualified as rigorous research. The interventions they evaluated included group discussions and/or counseling, peer-led group discussions,
educational role-playing, games, videos, or classroom-based sessions. Some interventions used a combination of these techniques. The researchers concluded that including youth peers in activities that are not classroom-based was more effective than other strategies in prevention initiatives.

Metrik and colleagues (2003) reviewed effective youth- and other-generated strategies designed to reduce and cease alcohol use among youth. They concluded that multiple pathways to recovery are most effective in influencing youth’s alcohol consumption. However, they stress that social support from family or social networks was influential in determining the success of interventions to minimize alcohol consumption. These researchers determined that the social and cultural repercussions for youth are significant in their decisions to avoid alcohol.

The preventative interventions that have been tried with youth are largely based on the principles of knowledge acquisition and motivation (Anderko and Uscian (2000). The implementers typically assume that if youth know the risks of unsafe behavior, they will avoid that behaviour. Research initiatives to evaluate interventions to prevent disease among youth have generally been short term, primarily measuring youth satisfaction and knowledge within a few weeks of the implemented intervention.

An example of such research is the study by Anderko and Uscian (2000) in which they assess the knowledge, motivation, and skills acquisition of college-aged youth in regard to the prevention of HIV and sexually transmitted diseases. The intervention included articles published in student newsletters and nurse-led in-class discussions, as well as on-campus condom distribution, free HIV testing, posters, and information booths. The respondents completed a pre- and immediately post-intervention questionnaire to measure their knowledge of HIV and STD prevention. In addition, they gave responses to an in-class scenario. They also
provided self-reports of prevention behaviors pre-and one year following the intervention. The researchers acknowledged limitations of the study as the reliance on self-reports, the lack of validity and reliability of the survey tools used in the study, and their inability to account for the unique effects of any of the multiple components of the intervention. They also identify a paradox in their data: youth stated they would decrease their high-risk behaviour because of the intervention but were generally naïve about the existence of such behaviours among their peers.

Dimitri, Garrison, Michelle, Ebel, Wiebe and Rivara (2003) conducted a systematic review of 81 randomized controlled trials of smoking prevention interventions (posters, small talks when visiting the clinics, anti-tobacco messages, newsletters sent out to clients) for youth that were delivered in medical or dental providers’ offices. Only four of these fit the authors’ criteria for scientific rigor. Two of these studies had been conducted in medical clinics and two in dental clinics. Of these four, only one demonstrated a significant effect on smoking initiation. Dimitri and colleagues conclude that there exists limited evidence of the efficacy of smoking prevention interventions in adolescence and that there is no evidence for the long-term effectiveness of such interventions. The authors suggested that the reason why the interventions had not been effective was that clinic staff was too busy to provide the guidance and support that youth needed for the intervention to be integrated in their lives. They did not specify if any of the researchers included youth representatives in designing the prevention messaging. A similar review conducted by Skara and Sussman (2003) utilized literature reviews and meta-analysis on interventions to prevent or stop tobacco smoking, and alcohol and marijuana use among adolescents. They investigated the effectiveness of psychosocial strategies in programs to prevent substance abuse in youth. They indicated that the multifaceted and unique nature of the interventions included in their meta-analysis was a challenge to the validity of their findings.
They conclude that many adolescents continue to abuse tobacco, alcohol, and marijuana despite interventions, because they "experience major biological, cognitive, social, and emotional changes that influence behavioural choices, such as experimentation with health-compromising substances" (p. 451). The meta-analysis findings were positive in that many of the programs they studied had acknowledged a decrease in substance use in youth as a result of the intervention. The researchers attributed the success of the school and community-based programs to their focus on youth’s psycho-social issues, and to the inclusion of youth in the design and implementation of the intervention. The researchers recommend that more qualitative studies take place to address the context and meaning of substance use among the youth population.

In a prospective study, Scal, Ireland, and Wagman Borowsky (2002) identified factors at the individual, peer, family and community level that predict and protect against smoking among a nationally representative sample of American adolescents. They specifically examined the differences in factors by gender and stage of adolescent development, as well as the interplay between the factors that increase risk, to better understand ways in which protective factors may attenuate the risk of becoming a smoker, using a prospective design. Scal and colleagues (2002) asserted that “prevention efforts that target both the reduction of risk factors and enhancement of protective factors for the individual, family, peer group and community are likely to reduce the likelihood of smoking initiation” (p. 80).

In summary, the successful prevention/intervention programs for youth have been those that included the youth in program planning, implementation, and evaluation. Merely teaching the youth about unwanted behaviors such as substance abuse will not prevent them from using them. It is also important to look at the networking of youth and to provide peer, or school-based, or community-based programming prevention programming for prevention. Finally, it is
important to target protective factors that include individual youth, their peers, and their family and community in prevention initiatives. In the following section, I discuss prevention initiatives that are targeted to First Nations youth.

**Prevention Initiatives with First Nations Youth**

Failure to protect a child from harm is perhaps the greatest shame that can befall an First Nations family. Yet it has happened repeatedly in the last several generations, and it continues to happen today (RCAP, 1996). The preceding statement was made in the context of a directive to protect First Nations children from harm. According to the RCAP (1996), in today’s society, we continue to fail our young people who one day will be our leaders. The number of interventions that are targeted for the prevention of disease or the avoidance of high-risk behavior among First Nations youth is minimal. Young (2003) discovered, in a review of research about First Nations health, that youth are not well-studied and that researchers have tended to focus on First Nations males on reserves. A survey conducted by Joseph (1999) on First Nations health issues in Vancouver and the Lower Mainland of BC determines the need for an First Nations youth action plan for supporting youth. The researcher’s report recommends that health care practitioners interested in disease prevention work with youth from the youth portfolio of the Vancouver Council (a council of First Nations organizations in the Vancouver area) to identify youth drug and alcohol treatment initiatives, develop plans to advance youth initiatives, identify and advocate for inclusion of First Nations youth in existing campaigns for preventing school and domestic violence, racism, and tobacco use, and ensure existing strategies in preventing teen pregnancies are appropriately responsive to First Nations teens.

The Canadian Aboriginal AIDS Network (2002) confirms that targeted HIV/AIDS Programs for First Nations youth need to be developed with active First Nations involvement in
all stages of the process” (CAAN, pamphlet, p. 2). Harper and Carver (1999) state that the “constellation of developmental tasks and life circumstances often leads educators to limit high-risk youth’s participation in research and evaluation studies to that of subjects, not collaborators” (p. 251). They maintain that high risk youth should be included in collaborations in order to ensure relevance and effectiveness. However, youth often do not feel as though they are part of the decision-making in a community (Brentro et al, 1990). In the Medicine Wheel, the Adolescent (youth) component presents youth as equal to all others; therefore, First Nations youth generally believe they have a right to an equal voice to adults in their community (ANAC, 2002).

Algert (2003) developed and evaluated an intervention to prevent nutritionally based diseases such as diabetes among Native Americans (equal to Status Indians of Canada) in the USA. The interventions focused on Grade 4-6 students, entailed a lesson plan for Native Americans on healthful Native traditional food and were delivered as part of an American history class (social studies). The objective of this lesson plan was for the children to learn about the nutritional values of their regional traditional foods and those brought by European settlers. The researcher suggests that when the children helped in preparing the foods, they enjoyed the food even more. They also learned that traditional foods were more nutritious than processed foods. The evaluation of this initiative occurred four times in each of the three grade levels with all 12 teachers. The outcomes of the intervention were that the children were able to define a traditional food and its nutritional value. However, the research did not focus on long-term outcomes, such as changes in the children’s eating patterns.

There are examples of disease prevention interventions used with First Nations people that have not been formally evaluated by researchers. One such example is Chee Mamuk, an
First Nations HIV/AIDS awareness (prevention) program that is situated at the BC Centre for Disease Control. This program initiated two youth projects in the spring and summer of 2002 (Chee Mamuk, 2002). The older youth project was entitled “Chako, Becoming of Age.” It ran throughout the month of July 2002. The youth were 18 – 29 years of age and were defined as at-risk, with beginning high-risk behaviors, such as intravenous drug use. The intervention in this project utilized culture, Elders and ceremonies to support the transition of youth into adulthood. Six youth participated in the project. They were required to participate in the program every day Monday to Friday 9am to 4pm for the month of July. Their tasks were to design their own regalia with respect to their own First Nations, make a drum, learn a cultural song, and present a gift for the agency that was funding them. Five completed the project successfully. One youth was not ready to commit to such a program as he still had addiction issues and was not prepared to stop his drug use during the project. Each week a First Nations guest speaker would come in and share health promotion messages with the youth. For example, one spoke about becoming HIV positive and how she is living with HIV today. One visitor shared his life experience being “two-spirited” and he taught about the traditional beliefs and values about being two-spirited. Cultural workers also came in to share their knowledge on regalia making, singing songs, drum making, and carving.

The five youth participants stated they regained self-esteem, a sense of community, cultural knowledge, and most of all, a pride of achievement in completing something because of the project. They and the project implementers produced a video recording of the project and the youth’s experience. Chee Mamuk has now gone into its third reproduction of the video and guidebook. A six month follow up telephone call to the youth participants provided insight as to the effectiveness of this program. Many of the youth acknowledged their positive change in
behaviour to avoid contracting diseases such as HCV. One youth, however, did not respond to telephone calls or emails about the long-term outcomes of the project.

Another Chee Mamuk intervention project included younger First Nations youth who were between the ages of 11 and 18. These youth were asked what messages they would like to provide their peers on the prevention of disease. The inclusion of Elders was important as they provided a guide for Chee Mamuk staff and youth in the development of the prevention messages. The youth developed a calendar, video, and a game as a result of this project. These youth learned how to work together on writing the script, acting, and editing the video. The group developed the game “Strengthening the Circle.” They decided on this name because they realized they are part of the circle, but felt they wanted to strengthen their part (quadrant) of the circle. They developed questions for the game that alluded to health promotion (strength of the First Nations culture), and the risk facts, (prevention), and what HIV/AIDS, STDs, and HCV are. They developed the game outline utilizing the medicine wheel, adding in animals for prize amounts. It is similar to the game “Jeopardy” in that questions are asked, but they relate to prevention of HIV/AIDS, STDs, and Hepatitis and also looks at what strengths First Nations people have to help with the issues surrounding risks.

Both of these Chee Mamuk projects were considered successful as the implementers continue to be requested to present these projects at First Nations conferences and workshops throughout British Columbia and Canada. Both youth projects utilized culture as a mode of health promotion, further preventing disease or preventing disease with tools that could be transferred to other First Nations communities. Elders were also considered an important part of the planning, implementation and evaluation of the projects.
Recently, there have been some new initiatives in developing culturally relevant print materials in the field of Hepatitis. The National Association of Friendship Centres and Chee Mamuk have developed Hepatitis brochures and information kits that try to capture the attention of First Nations people. However, these are print-based methods that reflect primarily adult issues, take considerable time to read, and require literacy. Another limitation in many of the print materials developed for First Nation people is that youth are generally not involved in the development of such materials. If youth are involved in such program development, they tend to be people who have not yet been exposed to unsafe practices.

In summary, I have discussed research-based and non-research-based interventions for First Nations people and First Nations youth. Anecdotal evidence suggests that successful interventions have been those that involved the First Nations culture and First Nations youth from designing to evaluation of the intervention. Since First Nation youth perceive themselves to be equal in the circle of decision making in an First Nations community, they demand to be heard and invited to participate in program planning (ANAC, 2002). Another equal quadrant in the Medicine Wheel is the Elder. In the following section, I will discuss Elders’ participation in program planning, research and evaluation.

**Elders’ Knowledge and Participation in Research**

Dickson and Green (2001) acknowledge that research is important; at the same time, they asked themselves, “Whose ‘benefit’ is research for?” They conducted research on a health promotion intervention utilizing Participatory Action Research with older First Nations women. They learned from the Elders, that “grandmothers held the perception of research, common to First Nations and other marginalized peoples, as something done to them for the benefit of outsiders, and from which they themselves receive no gain” (p. 472).
Turning to the Elders’ knowledge in respect to youth, an Elder from an Alberta Cree Nation shares his wisdom: When asked about the meaning of life, the Elder paused and responded, “Grandson, children are the purpose of life. We were once children and someone cared for us, and now it is our time to care” (Brentro, et al., 1990). This statement reflects the responsibility First Nations Elders are expected to assume in regards to the future of the youth in their community. Elders also find meaning in their own lives when helping others (Ambler, 2000). Sparks (2000) reminds us that Elders can be a wonderful resource who can provide positive images of Native American People. Having a positive image of oneself is important because without this one is at risk for disease. It also reflects the fact that Elders are expected to remember that they were once youth who needed protection and counsel.

The authors of “Research on HIV/AIDS in First Nations people: A Background Paper” recommend that the use of traditional Elders’ teachings is important to research when researching experiences of First Nation people. The authors go on to state, “Qualitative studies are needed which will provide rich data on the lived experience of First Nations people with HIV/AIDS. Cultural practices that affect the design and delivery of interventions need to be investigated, including the potential role of traditional First Nations medicine and the role of Elders” (p. 15).

Oral tradition is of particular importance, because many Elders may not have the educational background to be able to read. Underwood (1994) shares her experience of being in grade school and what it was like for her when her view of learning was not accepted. She was taught in the oral tradition in her home which she views as valuable; school learning was foreign to her. She was being taught from a textbook on Columbus, the explorer of 1492. She illustrates:

The oral history she was learning from her father was much more accurate than the “American Indian history” she was taught in third grade. What she learned from her
tradition was not at all what she learned at school. Yet her teacher refused to honour this. When she asked permission to say on the test, “my teacher says” or “the book says,” the teacher’s answer was, “No! I’m telling you the truth. You put it down that way.” Paula couldn’t bring herself to write down something she knew to be inaccurate, so she turned in a blank sheet of paper with her name on it, and got an F on the test. (p. 14)

In this section, I highlight the role of the First Nation Elders’ knowledge of culture and strength as ways to prevent disease, specifically in the development of interventions for First Nation youth. Culture is viewed by First Nation people as a strength (Van Uchelen, C. Davidson, Quresette, Brasfield, and Demerais, 1997). Cultural activities may provide an answer to the transmission of HCV in First Nations youth and guide the development of an intervention program to prevent HCV. I identify the benefits and limitations of involving Elders in the implementation of such interventions. Since HIV/AIDS is contracted in similar ways to HCV, some First Nation people view HIV/AIDS as a gift because it provides a lesson to the fight against diseases such as HIV/AIDS and HCV; for example it strengthens the spiritual foundations (Lambert 1993). Lambert adds, “Advice given by Elders has been to get back to teaching basic values to our children” (p. 46).

Wilson and Rosenberg (2002) determine from the First Nations Peoples Survey (1991) that although “much research has examined First Nations peoples’ health in Canada, few studies have explored the role of traditional activities in enhancing health” (p. 2017). There is a paucity of published writings about the use of traditional Elders in interventions to prevent disease; however, there is more written about the use of Elders in treatment. An important document in this regard is the report by Ellerby and Ellerby (1998) to the Solicitor General of Canada. These researchers investigated the role of Elders in sex-offender treatment in eight correctional facilities. They interviewed Elders, First Nations program providers, psychologists, treatment providers, and First Nations inmates who had participated in sex-offender programs. The Elders
were perceived by First Nations inmates and other participants as highly effective in such programs because they are non-judgmental, understand the origins and factors contributing to sexual abuse in First Nations communities, and interpret the offender’s behavior in the context of First Nations cultural understandings and mores. The critical role that Elders were thought to play was that of cultural liaison or translator. The researchers concluded that there is a need for others to explore creative ways in which First Nations Elders could be used to address the health needs of First Nations people.

First Nations students of an Infant Education and Care program from Malaspina College introduce Elders as, “the teachers of our traditional culture . . . their knowledge and experience enables our younger children to learn more about our Indian culture” (Ellerby & Ellerby, 1998, p. 1). They go on to say since there is no written record of all the traditional Elders’ teachings, these lessons were passed down orally, and since Elders had no formal teachings, we should accept the way Elders acquired their knowledge (oral tradition) and how they will use this knowledge to transmit it to youth.

A number of researchers have recommended that First Nations Elders provide a way of mediating First Nations people’s distrust of researchers and the research process (e.g., Commanda, 1998) that has arisen from their exploitation by researchers in the past. In recent years, the Canadian government has emphasized the need for First Nations people to be partners in the design and implementation of research (Reading & Nowgesic, 2002; Smye & Browne, 2002).

Summary

In summary, there have been many lessons learned by researchers and program implementers to assure the success of disease prevention interventions for First Nations youth. These include the
conclusions that such interventions should (1) involve both youth and Elders in all phases of the intervention design, implementation and evaluation; (2) focus on the strengths of First Nations youth; (3) integrate the traditional beliefs and values of First Nations people; and (4) acknowledge Elders as the knowledge keepers of First Nations culture.

There are large gaps in published scholarly literature about the prevention of HCV in First Nations people, specifically among First Nations youth. Much of the research has been located in unpublished discussion papers, reports, and surveys that are done by First Nations organizations or agencies that work with First Nations people. A great deal of prevention intervention research has not been scientifically rigorous and has not included First Nations people as partners in the research process. In conclusion, the lessons that are derived from related research in the fields of diabetes, cigarette smoking and HIV/AIDS were helpful in the research design and its implementation. The framework of the Braid Theory also was helpful guided data collection and interpretation. It is also important to keep in mind the encouraging quality of the youth (i.e., courage and strength), and to protect the youth and Elders from harm, therefore, including not only research ethics, but First Nations protocol on research, plus nursing ethics as well.
CHAPTER THREE: METHODS

In this chapter, I provide details regarding the research design, including the research approach, the nature of the sample, the data collection and analysis strategies, rigor, and ethical considerations for the study. I explicate how the decisions about research design were made in accordance with First Nations people's traditional beliefs and their needs for inclusivity in research.

Methodology

In this section, I discuss the research approach, sample, and the strategies for recruitment, data collection, rigor and data analysis in the study. First, I describe the qualitative research approach of ethnography. Second, I describe the research design, including the sample and recruitment methods, followed by the data collection and data analysis strategies. The chapter concludes with a discussion regarding ethical considerations, rigor and limitations of this study. Throughout the chapter, utilizing a community based research approach, I emphasize why it was important to include First Nations people in research as partners in the planning and implementation of research.

The expectation of this research was to develop recommendations for the prevention of HCV for First Nation youth. The research provides a model of how health care providers and First Nation community members can come together to develop such prevention initiatives. Nichols (2002) notes from her research on participatory program planning and evaluation that including community members in research can do more than inform research; their involvement allows them to become active participants in addressing their circumstances. Since substance abuse such as injection drug use (IDU) is the major mode of transmission of HCV, Shah (2003) concludes that the development of effective health promotion programs, in relation to substance
abuse, should be participatory. In the following sections, I discuss how my research accomplished the task of developing recommendations for prevention initiatives for First Nations youth on HCV involving participation of youth and Elders.

_Ethnography Research Approach_

Qualitative research was appropriate for this research because little is known about the phenomena of First Nation youth risk taking and how First Nation Elders and youth can help in developing recommendations on the prevention of HCV (Morse, 2002). Shah (2003) states that, "many important issues in public health cannot be adequately addressed by quantitative methods" (p. 49). Silverman (2000) cautions researchers that qualitative research is useful for some research, however, there are other research methods that work just as well, "in fact, the choice between different research methods should depend upon what you are trying to find out" (p. 1).

The research approach used for this study is ethnography, a method of research that has its foundations in the discipline of anthropology. According to Burns and Grove (1997), this research approach provides a mechanism for studying "ways of living, ways of believing, and ways of adapting to changing environmental circumstances" (Burns & Grove, p. 77). Mayan (2001) suggests that the outcome of ethnography is "a thick description of the nature of a phenomenon" (p. 8). It is the cultural and in-depth focus of ethnography that contributed to understanding the culture of First Nation youth and how their cultural understandings and environmental changes influence their perception of HCV risk behaviors. As Beckmann and Murray (1993) suggest, peer groups or friends of the same age influence adolescents to a greater extent than parents, media, teachers, or other adults. This suggestion is also applicable to the cultural beliefs, ways of living and understanding of First Nation youth who provide insight in
developing recommendations or interventions to prevent HCV. Ethnography is appropriate because the research focuses on First Nations people's cultural beliefs and practices, community, risk factors for HCV, and how nursing culture can find a way to provide an intervention on HCV in the First Nation youth population.

The most important aspect of using ethnography research methodology was the inclusion of First Nation youth and Elders in sharing their strengths of being First Nation, together with youth's knowledge of what puts them at risk, and Elders' sharing their wisdom of prevention from their cultural perspective. Polit and Hungler (1993) inform nursing researchers that "the aim of the ethnographer is to learn from (rather than to study) members of a cultural group—to understand their world view as they define it" (p. 327). They indicate that the ethnographic researcher "focuses on the culture of a group of people. An underlying assumption of the ethnographer is that every human group eventually evolves a culture that guides the members' view of the world and the way they structure their experiences" (p. 327). The ethnographic method of research permits a culture to evolve and guide a group of people; it also provided a way for this researcher to collaborate with First Nations Elders and youth in the prevention of HCV.

There are two methodological approaches in Ethnography: first emic, which looks at studying behaviors from within the culture, and secondly etic, which looks at "studying behaviors from outside the culture and examining similarities and differences across cultures" (Burns & Grove, 1997). My study mainly entailed the emic approach because I am First Nation and a nurse, and examined First Nation risk behaviors within my own culture. Polit and Hungler (1993) also emphasizes that the "emic perspective refers to the way the members of the culture themselves envision their world—it is the 'insiders' view" (p. 327). In addition, they go on to
write, “Ethnographers strive to acquire an emic perspective of a culture under study, generally through participant observation and in-depth interviews “(p. 327). The inclusion of my Braid Theory gives credibility from an insider perspective. There are subtle variations in First Nations’ beliefs and ways of knowing that depend on the generation, education, and setting (i.e., rural/urban, reserve/non-reserve). My cultural experiences are ways informed by another generation and perhaps form a different context than that of some of the youth involved in the research. Although I am not completely an outsider as I am First Nation, as Kauffman, (1994); Beckmann and Proctor Zentner (1993), point out, ‘outsiders’ who are born into one’s group membership or social position either have privileged access to knowledge, or are wholly excluded from it. As a First Nations woman I gained the trust of the youth and obtained accurate information from them.

Browne (1997) explored the meaning of respect with Cree-Ojibwa informants of Northern Manitoba, for the implications of respect as a concept in nursing. She emphasizes the need for nurses to be aware of sociopolitical factors that can affect the quality of interactions between First Nations clients and Western health-care providers. She continues that nursing can “realize its commitment to the value of status equality, inherent worth, and the dignity of persons” (p.107). By integrating the First Nation protocol of respect in the research, I was able to gain the respect of Elders and include them in the research process.

Community Based Research

Community Based Research (CBR) plays an important role when including those research participants who do not share the same education or perspectives as the researcher. For example, Elders may not have had the same education as the researcher, and the youth may be too young to have gained the knowledge of the researcher and Elders. CBR includes the ideas,
participation and input from those being researched. In the following section I explain why CBR is important in this research.

Allman, Myers and Cockerill, (1997) contend that CBR comes in many forms; it “may incorporate either full action, varying degrees of empowerment, or, at the other extreme, nothing more than the permission of an involved community regarding any one particular research initiative. They view CBR as an ideology that allows for flexibility. The CAAN (2003) defines CBR similarly, adding, “CBR is a form of research whereby First Nations community collaboration, direction, participation and commitment are essential” (www.caan.ca). CAAN also emphasizes that First Nation participation should be demonstrated in all stages of the research process including identifying research questions, collecting and analyzing data, and reporting results.

Therefore, in this study, the First Nation youth and Elders were involved in identifying the research questions, validating the data the researcher collected and communicating with the researcher on where and who to report to and apply the results. The overarching question the First Nation youth and Elders were asked was, “What do you consider to be a culturally relevant prevention program for First Nation youth?” The research was guided by the values of respect, community involvement, community relevance, equity in partnership, methodological rigor, and an ethical review (www.caan.ca, 2003). Ethnography or any type of research with First Nations people demands these principles and the inclusion of such tenets has strengthened the research.
Research Design

Sample and recruitment

Several critics of research among First Nations people have noted that it is important to include the people being studied in the planning and implementation of the research (King-Hooper, 1995). This has been a criticism of much health care delivery and programming among First Nations people. For example, King-Hooper and colleagues (1995) suggest that First Nation people have been excluded from making health-care decisions. They maintain many agencies have been ineffective because of a lack of a strong cultural base. Accordingly, in the proposed research project, the intervention to be developed will include the voices of several First Nation representatives, including youth. This will allow other youth to gain insight from peers on the prevention of HCV. Beckmann Murray and Proctor Zentner (1993) claim that adolescent peers can serve as models for skills not yet acquired.

The study sample was comprised of First Nation youth and First Nations Elders. The sample included:

- 15 First Nation youth at risk between the ages of 13 – 17
- 8 Traditional Elders (formally recognized as such in the First Nation community)

The inclusion criteria for the sample was that they reside in Vancouver or the Lower Mainland of British Columbia, speak English, and were able to articulate their experiences and understanding of why First Nation youth place themselves at risk for HCV and what strategies would be effective in preventing such behaviours. The eight Elders were interviewed in a focus group setting as they did not want to be interviewed individually.

The Elders were recruited first, and they helped to determine which youth to interview. The criteria of “Elder” describes those individuals who are respected and known by First Nations
people for being valued and admired for their wisdom and experience. The Elders had some experience in working in communicable disease and understood the First Nations culture. In addition, the Elders exemplified the cultural beliefs and values of being responsible Traditional First Nations Elders. As a First Nations person who has worked with many traditional Elders in the areas of HCV and HIV in Vancouver and the Lower Mainland, I was aware of several people who met the criteria for Elder. I sent them a description of the study and requested them to contact me if they were interested in participating in the study. The focus group took place at an Elders’ gathering place in New Westminster. Before the focus group began, an Elder offered a prayer; a prayer was also said at the end of the focus group interview. The Elders all came from different Nations from across Canada (see Table 1.1 for Demographics of Elders). Since the Elders wanted to be interviewed in a focus group format, I was not able to assign them individual codes; therefore I gave the Elders one code to represent all of them. They spoke sometimes in unison as they were excited to provide the information. I chose to have the tape recorder on with their permission during my presentation to them on HCV because I knew they would freely give information as it pertained to the topic at hand.

The youth were recruited using the advice of the Elders. The Elders had worked with the youth in question, and they knew of youth who are at risk, and youth who have not yet experienced being at risk. The Elders suggested places where I should interview the youth; for example: Indian Centre, Family Place, youth Detention Centre, Alternative Schools, youth Detention Houses, on the street, on the local Lower Mainland reservations and in regular schools. With the Elders’ advice, I developed a recruitment poster (Appendix II) that I sent via email to many different First Nations organizations and also brought with me in person to different gatherings such as pow wows, meetings, and other events.
The majority of the youth who participated are considered high risk First Nation youth. First Nation youth who were not considered high risk (for example, those who live at home with one or two original parents and attend school) also participated, so that I might obtain a different perspective on risk and prevention messaging.

Fifteen First Nation youth between the ages of thirteen and seventeen (13-17) years of age participated. The youngest female who participated was 13, while the youngest male was 15 and the oldest 17 from each gender.

The youth were mainly living with someone other than their own birth parents, with the exception of three females who lived with their mother and father, and one who was living with her mother. One young girl who was 15 years old lived on her own with her boyfriend. Eight of the youth were living in adjudicated homes or detention centres. One male lived in a foster home, while the others lived with grandparents.

Even though the youth reside in the Lower Mainland, they come from different First Nations from across Canada such as Squamish (Squamish), Swamppee Cree (Manitoba), Cree (Alberta), Manitoba/Finland (this youth does not know which First Nation he comes from as he grew up in foster homes), Cree (Saskatchewan), and Nuu chah Nuulth (Coast Salish), and Dene (Manitoba). The Table 1 outlines the youth’s age, gender, place of origin, current residence, and place of interview and whether they participated in a group or individual interview.
Table 1: Demographics of First Nation youth and Interview Process

<table>
<thead>
<tr>
<th>Youth</th>
<th>Age</th>
<th>M/F</th>
<th>Originate</th>
<th>Current Residence</th>
<th>Place of Interview</th>
<th>Group/Individual Interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>FNG1a</td>
<td>17</td>
<td>F</td>
<td>Cree/Alberta</td>
<td>Vancouver</td>
<td>youth Group Home</td>
<td>Group</td>
</tr>
<tr>
<td>FNG2b</td>
<td>17</td>
<td>M</td>
<td>Nuu Cha Nuulth</td>
<td>Vancouver</td>
<td>youth Group Home</td>
<td>Group</td>
</tr>
<tr>
<td>FNG3c</td>
<td>17</td>
<td>M</td>
<td>Squamish</td>
<td>Vancouver</td>
<td>youth Group Home</td>
<td>Group</td>
</tr>
<tr>
<td>FNG4d</td>
<td>17</td>
<td>M</td>
<td>Tnuxa Kinbasket</td>
<td>Vancouver</td>
<td>youth Group Home</td>
<td>Group</td>
</tr>
<tr>
<td>FNII#5</td>
<td>13</td>
<td>F</td>
<td>Cree/Saskatchewan</td>
<td>Burnaby</td>
<td>Kwantlen Pow wow</td>
<td>Individual</td>
</tr>
<tr>
<td>FNII#6</td>
<td>15</td>
<td>F</td>
<td>Cree/Alberta</td>
<td>Vancouver</td>
<td>Kwantlen Pow wow</td>
<td>Individual</td>
</tr>
<tr>
<td>FNII#7</td>
<td>17</td>
<td>F</td>
<td>Gitksan/unknown</td>
<td>Vancouver</td>
<td>First Nation Employment Ctre</td>
<td>Individual</td>
</tr>
<tr>
<td>FNII#8</td>
<td>17</td>
<td>M</td>
<td>Dene/Manitoba</td>
<td>Port Moody</td>
<td>Personal Home</td>
<td>Individual</td>
</tr>
<tr>
<td>FNII#9</td>
<td>15</td>
<td>F</td>
<td>Cree/Alberta</td>
<td>Vancouver</td>
<td>Alternative School-Vancouver</td>
<td>Individual</td>
</tr>
<tr>
<td>FNII#10</td>
<td>17</td>
<td>F</td>
<td>Nisga’a – Haida</td>
<td>Vancouver</td>
<td>Alternative School-Vancouver</td>
<td>Individual</td>
</tr>
<tr>
<td>FNII#11</td>
<td>16</td>
<td>F</td>
<td>Cree/Inuit – Tshimsian</td>
<td>Vancouver</td>
<td>Alternative School-Vancouver</td>
<td>Individual</td>
</tr>
<tr>
<td>YDC#12</td>
<td>17</td>
<td>M</td>
<td>Finnish/Unknown</td>
<td>Burnaby</td>
<td>youth Detention Centre</td>
<td>Two in a Group</td>
</tr>
<tr>
<td>YDC#13</td>
<td>17</td>
<td>M</td>
<td>Squamish</td>
<td>Burnaby</td>
<td>youth Detention Centre</td>
<td>Two in a Group</td>
</tr>
<tr>
<td>YDC#14</td>
<td>17</td>
<td>M</td>
<td>Lil’Wat</td>
<td>Burnaby</td>
<td>youth Detention Centre</td>
<td>Two in a Group</td>
</tr>
<tr>
<td>YDC#15</td>
<td>17</td>
<td>M</td>
<td>Unknown First Nation Status</td>
<td>Burnaby</td>
<td>youth Detention Centre</td>
<td>Two in a Group</td>
</tr>
</tbody>
</table>

Compensation has been an issue in research for many years. Many First Nations people are not employed, therefore a small honorarium was provided for their time and travel. In my personal experience as a First Nations person, I know that it is important for researchers to not state openly that they are paying someone; instead I stated something like, “This is ‘gas money’ for your time and travel.” The money provided was therefore not a ‘purchase’ or form of coercion to obtain information from the participants. Many First Nations people, if given the opportunity, enjoy and appreciate sharing their knowledge with others, especially when it is done with respect.

Twenty three First Nation people in total were recruited and interviewed one to two times in face-to-face interviews that were tape recorded. I provided the participants with a presentation on all aspects of HCV before the interviews took place so they could more freely provide information on how to prevent HCV and why First Nation youth are at risk. In addition, an
information letter and consent form were reviewed with the participants so that their understanding of their participation was fully informed (Appendix III, a, b, c). The information letter and consent were written in different formats for each participant group. For example, one was written for the Elders in simple English, another for the youth who consented for themselves as they no longer live at home. Written Consents are required from the ethics board and oral tradition was not accepted as a form of consent. Ethical approval has been obtained from the University of British Columbia. A detailed outline of the data collection process follows.

Data collection

Face to face interviews were recorded with the participants, who were asked to share their knowledge and understanding of why First Nation youth take risks that may result in HCV and what prevention recommendations for HCV should ideally involve. The data collection from this study primarily included one to two in-depth in-person interviews with each participant. The interviews were tape recorded with permission from the participants. I, the researcher, conducted all of the interviews. The interviews were conducted in different environments. For example, two interviews were at a pow wow, four at an adjudicated house for youth at risk, three at an Alternative School, four at a youth detention centre, and finally three at a private location selected by the participants. I incorporated the suggestion of Rubin and Rubin (1995), that interviews be conducted in a small room where we also shared a snack (juice and cookies). This sharing of food is also in keeping with First Nations culture; hence food was shared in all interviews.

Questionnaire and interviews

I set up a meeting with the Elders first and asked them to help me define the research questions, where to locate the youth and to discuss how to approach the youth. I also asked the
Elders their perspective on why First Nation youth are at risk for HCV. The quotes are direct quotes to get the feel of the Elders’ language, their concern and their knowledge of youth at risk.

To begin, I will share what the Elders felt was important to ask the youth. The Elders expressed that the questions needed to be:

Open ended questions. By that I mean that the uh, it involves in regards to exploring; I guess what that meaning is for them? In other words, not just a yes or a no, but because in a sense that involves blame and guilt and shame. And so we want to, I guess in a sense look at it from their point of view. Not so much the parents’ point of view, or the adult’s point of view, but in regards to what does it mean for them? I guess in terms of taking part in an effort in those risks, about drug use and about their sexual identity and their sexual behaviour. And not to mention criminal, are they involved in the criminal behaviour because that’s a reality for some of them, eh? In terms of violence (EFG).

Another Elder expressed the importance of adding questions on what causes the youth to take risks, the Residential School experiences the parents or grandparents had that impact on the youth, and the parents’ behaviour’s effect:

And having to look at the main causes for the young people today, and to talk about the generational impact of the sexual abuse. Drug and alcohol inhibitions as well as the battery and the violence, the domestic violence in the home. And the separation to divorces and what this creates for the children themselves. And the feeling of not caring, you know so you ask them then, ‘Okay now, what do you feel of your hurt, pain and anger that drives you to alcohol and drugs? That drives you to the point where you don’t care if you catch anything? Or not, of HIV and AIDS? Those kinds of questions . . . are you willing to find some way of preventing or finding a way of healing yourself? Do you think that you will find western medical services worthy or cultural or spiritual? (EFG).

One interview was conducted with each First Nation youth participant, with the exception

One interview was conducted with each First Nation youth participant, with the exception of one youth who came back to me unbidden with hand written notes on the questions asked of him the previous day. I also made an appointment to go back to the Adjudicated House for First Nation youth; however, they were not willing to share information at this time or for clarification of what was said in the previous interview. It was difficult to locate the youth after the first interview as they were mainly adjudicated to their environments (detention
houses/centres/alternative schools). Following the advice of the Elders face-to-face interviews employed open-ended questions, which allowed the youth to tell their stories in their own way. Hammersley and Atkinson (1993) contend that ethnographic data are not structured but rather are open-ended verbal descriptions in field notes, of transcriptions of audio- or video-recordings, and/or extracts of text from documents. The interviews were transcribed verbatim.

Once the initial interview to gather the data occurred and was transcribed, a second interview was attempted, however, I was hindered by the youth’s situations in adjudicated environments, living in foster homes, living on their own, or being hard to reach because they did not have telephones, made it hard to schedule follow up interviews. The one participant I was able to interview a second time received the transcription of the first interview for her review on the accuracy of the transcription and information gathered. I also asked for clarification of any data from the first interview and probed themes emerging from the analysis. I also posed questions that have been generated in interviews with other participants (e.g., some people have suggested “X . . . What is your response to this suggestion?”). The youth previously mentioned, who brought back two pages of hand written answers to the questions asked the previous day, said, “I could not answer all your questions and went away to write this out for you” (FNII#7). He also brought back information from the ‘shoebox’ of cultural material he had on his home community from a Northern Manitoba First Nation which he has never had the opportunity to visit and whose culture he has never experienced first hand.

The interviews were carried out in accordance with guidelines provided by Rubin and Rubin, who suggest that interviews must have three components to ensure in-depth inquiry and information gathering: main questions, probes, and follow-ups (1995). In such a framework, questions are guides for conversation. Having guiding questions (Appendix III) and a data
collection checklist developed keeps the interviews on course and at the same time allows for flexibility to explore uncharted paths (Rubin and Rubin, p. 16). According to Rubin and Rubin, interviewers should ensure that they detail the main questions to be asked prior to the interview, cover the entire subject, flowing from one topic or focus to the next, and ensure that the interview questions are congruent with the research design.

Probes are questions that help the interviewee know that it is okay to elaborate, allow for in-depth questions, and also to finish the current question being asked. Follow up questions allow the interviewer and interviewee to pursue themes discovered, elaborate on the context of answers, and explore the implications of what has been said. Rubin and Rubin (1995) believe that the interview questions should be limited so that the interviewee does not feel overwhelmed (p. 123). Appendix III identifies the questions identified to guide the interviews. Initially, my questions were very numerous as the Elders wanted the youth to provide all the information that relates to why the youth take such dangerous risks with their lives. As themes started to emerge, the interview questions became more focused.

Ethnographic research includes field notes; I wrote notes during the interviews with permission from the participants. These notes only reminded me of what was said. I filled in the tone and body language being used following the interviews, which however meant it would be embarrassing to ask a participant if my field notes were accurate. To avoid embarrassment and to ensure accuracy, before each interview, I informed the participants that my notes were reminders to myself, and that if they would like to know what I was writing I would certainly provide this to them, as this would also provide me with clarification of my thoughts from the notes, and could only serve to enhance my research. Emerson, Fretz, and Shaw (1995) identify the discomfort in note taking: “People may be uncomfortable with a jotting researcher because
they have little experience with writing as a part of everyday life. Especially in oral cultures, watching and writing about people may seem like a strange activity indeed” (p. 25). Also, from my personal experience in listening to stories, it seems disrespectful to write while listening to someone talk; how can you hear the person talk if you are writing things down? Kouritzin (2002) also emphasizes that “the language used in field notes has numerous long-range consequences for your research” (p. 124). Kouritzin cites Lapadat & Lindsay (1999) as saying, “in a manner similar to verbatim transcriptions, field notes are interpretations or representations that follow from the purposes and working theories of the researchers, as well as from general assumptions about the transparency of language” (p. 124).

The tones and body language of some of the participants were sometimes quiet, with long pauses between answers, to the opposite extreme of being very talkative. Some youth and Elders became fidgety when talking about specific topics such as drugs, addiction, and sex.

In my experience, Elders will occasionally start telling a story that they feel relates to the topic at hand. In the First Nations way, it is disrespectful to interrupt them. Because the information is important to the Elder, it is also important to take that lesson and to learn from it. The learning may not be immediate, but, down the road, you may remember the story and how it actually fit with the current conversation and be thankful you did listen. The Elders do not always provide an answer to their story; it is up to the listener to interpret it in their own way, and what meaning it has for them. With this in mind, the following paragraph provides a guideline for the structure of my questions.

First Nations people typically take their time in answering questions. First Nation people do not blurt out answers so as not to sound stupid, in case the answer may not be what the other person is wanting or that it is simply wrong. Rubin and Rubin (1995) indicate that it is important
for the researcher to take turns speaking and wait for the interviewee to somehow inform the interviewer that their answer is complete before posing another question. In the following section, I discuss how the data is analyzed, followed by ethical considerations, methodological rigor and finally, the limitations of the research.

**Data analysis**

"Balanced walking requires the balanced progression of left foot, right food, left . . . It is the same with balanced thinking" (Underwood, 1994, p.25).

The previous quote reminds us to bear in mind, while analyzing the data, that the participants are First Nation. While this project is academic the findings must also be relevant to the world of First Nation youth; a balance between these perspectives must be maintained. Once the interviews were transcribed and the data verified by the available participants as accurate, a systematic coding system was used to find themes. Themes taken from the data helped to inform the recommendations on intervention programs on HCV for First Nation youth.

This section outlines the data analysis technique I used for this research. Roper and Shapiro (2000) ask the question, “How does coding begin?” (p. 94). The data analysis strategy I utilized was based on the work of Hammersley and Atkinson (1993) and Roper and Shapiro (2000), known for their ethnographic research worldwide (Morse, 1994, p. 225). According to these researchers, data analysis is not a distinct stage of the research; rather it begins at the very start of the researcher’s formulation of questions and clarification of research problems and continues. They go on to state that data analysis starts to take shape when notes are taken and the hunches of the researcher begin to emerge. Therefore, the data analysis spanned the research project. My research data analysis involved unstructured data, which mainly came from interviews with open-ended questions and field notes taken during the interview.
The formal data analysis consisted of simultaneously developing a set of analytic categories that captured relevant aspects of these data, and assigning particular items of data to the categories. Hammersley and Atkinson describe data analysis in the following way:

Data analysis requires several readings to become familiar with the data. Patterns are then identified; whether items may stand out as surprising or puzzling; how the data relates to what one might have expected on the basis of common sense knowledge, official accounts, or previous theory; and whether there are any apparent inconsistencies or contradictions among the view of different groups or individual, or between people’s expressed beliefs or attitudes and what they do. (1993, p. 210)

Next, more analytically significant data was funneled out or coded. Roper and Shapiro (2002) explain in general terms that “it is helpful to formulate basic domains that can categorize a broad range of phenomena when you are beginning the coding process” (p. 94). Potential coding domains include: setting, activities, events, general perspectives, specific perspectives related to the research topic; strategies, process; meanings and repeated phrases (p. 95). My research domains utilized these coding ideas.

It was important when I was coding to remember the research question. The question this research was asking Elders and youth was, “What are culturally appropriate HCV prevention recommendations for First Nation youth?” However, Roper and Shapiro agree that, even though the research question must be kept in mind, “unexpected questions or concepts that emerge during the conduct of the ethnography,” may arise (p. 94). The unexpected findings are discussed in the Findings, Chapter Four.

I sorted the patterns in the research data as previously stated, by sorting and grouping the descriptive labels into smaller number of sets, which now incorporate several discrete codes and became more general and abstract as patterns explaining regularities in behaviors and beliefs emerged. I then looked for patterns that became apparent as the information was sorted into
groups (like and unlike each other). Recurring relationships were then looked for, formulating a preliminary hunch or hypothesis.

Outliers are data that do not fit with the research question. These outliers will be kept and used to compare or test the findings of the research, which will strengthen the research. I did not find any outliers and used all the data as part of the answers to the questions being asked of the participants. Finally, I looked for more abstractions that explain and link to emerging constructs or theories from the data. Generalizing constructs and theories aim to discover an abstract network or interrelated concepts that explain the events and activities that I was told about by the participants.

Finally, memos, or reflective remarks were used in the margins of the transcripts of each interview with the other generalizing: constructs and theories, outliers (themes that do not fit) and sorting for patterns. Memos were ideas or insights I had when I reviewed the data. Memoing assisted in pulling commonalities and connections between the data collected. Memoing collected throughout the research process also helped me to more deeply and meaningfully understand my data.

**Ethical Considerations**

My research required putting into practice ethical and moral research guidelines with First Nation youth and Elders. As I have stated throughout, there is a long history of disrespectful and insensitive research on and for First Nations people. Issues in research with First Nations people include coming to the table of universities for discussion, and acceptance of First Nations protocol. From a nursing perspective, Fowler (1989) indicates “ethics and nursing have been bound to one another since the inception of modern nursing” (p. 955). Not only has this research
followed the code of ethics for nursing, but also of the ethical and moral beliefs of First Nations people—always respecting and protecting the youth and Elders from harm.

Jurgens (2002) asserted that, “According to ethical principles, individuals in society should have accurate and comprehensive information on all matters that require decision, choice, and action” (p. 11). The youth signed informed consent; written, informed consent was obtained from all participants. Parental consents were also obtained for youth who are not emancipated.

Fowler (1989) believes informed consent includes “helping to relieve moral uncertainty by clarifying the questions and by illuminating the ethical features of the situation, thereby providing a measure of comfort” (p. 957). I ensured that the purpose of the study was clear by explaining why informed consent was needed in research, as it is very important when working with First Nations youth and Elders. Many First Nation youth and adults in the First Nation community also suffer Fetal Alcohol Syndrome/Fetal Alcohol Effects (FAS/FAE) (Square, Chudley, and Moffat, 1997), which puts them at added risk for HCV. Someone with FAS/FAE may not have the competency level to fully participate in research. A moral decision was made in consultation with the Elders on refraining from utilizing First Nations youth with FAS/FAE. The study instead targeted only participants who were able to provide informed consent and to participate fully in the interviews.

Methodological Reliability and Validity (Rigor)

Morse and Field recognize (1995) that qualitative research has not been accepted widely by the academic world because of the “lack of control over the validity and reliability of the findings” (p. 143). This consideration has prompted qualitative researchers to develop what is now known in qualitative research as “rigor,” to ensure reliability and validity are achieved in qualitative research. Morse and Field (1995) describe how the verification of qualitative research
requires four elements in order to be valid (p. 143): a) truth value, b) applicability, c) consistency, and d) neutrality. I used Morse and Fields' description of verification for this study to ensure rigor was achieved:

a) Truth value reminds us that we must report the perspectives of the participants as clearly as possible;

b) Applicability requires that the research findings must be applicable to others;

c) Consistency requires that the findings must stay consistent if the inquiry were replicated with the same subjects or in a similar context;

d) Neutrality, or confirmability, refers to the freedom from bias in the research and results.

It is important to define reliability and validity (rigor) in qualitative research. Validity is defined by Bernard, 1994, (cited in Roper and Shapiro, 2000) as the “accuracy of the methods used to collect and analyze information collected during research . . . Validity is a major strength of the ethnographic process if the results reflect the reliability and meanings of the group studied”. Roper and Shapiro remind us that the use of ethnography involves the input of the participants in the study and since they are validating their input that the research will be valid (Roper & Shapiro, 2000). As described earlier, Mayan 2001 says of ethnography that it is “a thick description of the nature of a phenomenon” (p.8). It is the cultural and in-depth focus of ethnography that contributed to understanding the culture of First Nation youth and how their “cultural understandings and environmental changes influence their perception of HCV risk. This also increased the validity of the proposed study.

Reliability is defined by Brink & Wood, 1994, (cited in Roper & Shapiro, 2000) as meaning “that methods of collecting data are consistent, stable, and repeatable” (p.83). The data
that I collected has the criteria of consistency, stability, and is repeatable to other First Nation youth. The interviews with the participants were held at different events, wherever the participant felt comfortable, which allowed for collection of systematic data and confirmation and confidence in the findings. Roper & Shapiro (2000) agree ethnographic research is strengthened in validity and reliability when the investigator “has the opportunity to observe many events and to interview people multiple times during the extended period of data collection” (p. 83).

The following section discusses some of the limitations that occurred in the study.

Limitations

First Nation youth from the Lower Mainland were interviewed, creating some missed opportunities for those youth that live in other regions of British Columbia (urban and rural). Only First Nation youth at risk for HCV were interviewed with the exception of two youth who live with parents and were not considered at risk because of their guardianship.

A major limitation in this research is the inability to comprehensively represent the diversity of First Nation people from across Canada (approximately 600 bands nationwide), as well as the Métis and Inuit people. Métis is a French word that means mixed ancestral blood of French persons and First Nation; however, many non-French with mixed First Nation blood are claiming Métis status, for example, second generation Ukrainian and First Nation blood. This is a contentious issue with First Nation and Inuit people, because anyone can claim Métis status. Also, Inuit people are scarce throughout British Columbia.

Another limitation to this study is that the experience and needs of all First Nations people are not the same. As Wilson and Rosenberg (2002) explain, “Due to the essentialized categorization of First Nations identity, it is not possible to explore this relationship for different
First Nation groups, such as the Ojibwa, Mohawk and Dene” (p. 2028). They also go on to state that “the categories North American Indian, Métis and Inuit are not sufficient for acknowledging the distinct identities within each group” (p. 2028). Given that I interviewed 24 First Nation Elders and youth, the study does not include representatives of all First Nations people or their experiences. The study excludes Métis and Inuit representation and is limited to First Nation people.

Although being First Nation ancestry is a strength for me, the researcher, I am no longer a youth. Kauffman’s (1994) experience with ethnography research explains that outsiders “frequently err by underestimating the effects of ethnicity, age, and class on Insiders’ responses” (p.179). Kauffmann goes on to explain, “Researchers as Outsiders often mistakenly assume Insiders to be either ignorant, illiterate, or uneducated, thus patronizing the group, or well-educated, in which case they treat the group with unseemly deference ”(p.179). I can consider myself an Insider without being the age of the youth participants because of my same lived experience of being First Nation. On the other hand, as Hammersley and Atkinson (1993) point out, a danger in including the more sophisticated participants is the greater the tendency for him or her to move away from description into analysis. The participant sophistication with being at risk will be discussed further in the findings.

Recruiting youth between the ages of 13 – 17 who wanted to share their story proved to be challenging. As Harper and Carver (1999) point out, “this may be due, in part, to the sometimes unpredictable and unconventional behaviors in which adolescents engage” (p. 251). During the focus group with the First Nation youth, there were different personalities amongst them and sometimes some followed the lead of one of the other youth’s behaviours. For
example, if the leader was quiet, the rest of the youth were quiet, and once the leader in the group spoke, the rest spoke.

Summary

In summary, I detailed in this chapter why I chose the qualitative research approach of ethnography and how this fits with the research question. I discussed the utilization of Community Based Research with First Nations people, particularly with First Nations youth and Elders. I emphasized why it was important to include First Nations people in the research as partners in the planning, implementation and evaluation of research. I described the research design, including the sample and recruitment methods, followed by a description of the data collection and data analysis strategies. The chapter concluded with a discussion regarding ethical considerations, reliability and validity (rigor) and the limitations of this study. The chapter emphasized the importance of practicing First Nations protocol when doing research with First Nations people and keeping in mind the participants’ safety.
CHAPTER FOUR: FINDINGS

Overview

The goal of this investigation was to explore why First Nation youth who reside in the Lower Mainland of Vancouver take risks that lead to HCV. Another goal was to find out from traditional Elders why First Nations youth are at risk and what recommendations they can provide for the prevention of HCV. All the youth and Elders who participated originated from different First Nations from across Canada. Major themes emerging from the analysis include: surviving risky lives; in search of positive role models; being a First Nation youth means taking risks: being a member of a culture whose traditions have been eclipsed by violence, drugs and alcohol; accessing health care; and the awareness of HCV.

Once guidance was accomplished from the Elders' focus group and appropriate questions determined, the youth were interviewed. The sample included eight male and seven female First Nation youth with ages ranging from 13-17 years. The interviews took place at different venues, wherever possible at locations of the youth’s choosing. The interviews took place between July and December of 2004 in the Lower Mainland.

I begin the description of the findings by outlining the Elders' views on why First Nation youth are at risk and what recommendations they wish to share with health care providers regarding the prevention of HCV. Having detailed the Elders' views, I describe the tone of the interviews I conducted with the youth and discuss the emotions and in-depth information that surfaced. I examine the similarities or differences between the Elders and youth’s input, describing the five themes that emerged for both Elders and youth as key elements in the prevention of HCV. The chapter closes with recommendations for a culturally relevant prevention program on HCV among First Nation youth that could be used by health care
providers, youth and Elders. In the presentation of findings, codes are used to denote the type of interview. For example, I indicate an Elder’s focus group with the code EFG#1.

Elders’ Guidance on Risk Taking and HCV Prevention in First Nation youth

Eight Elders participated in my research. They chose to use a focus group format to share their information with me. Six female and two male Elders participated. The focus group took place at an Elders’ centre in New Westminster, British Columbia.

The quotes are taken from recordings I made of the Elders’ interviews and from field notes taken during the interview. The Elders did not want to be represented individually, but as a group. Therefore, I have presented what was said in the focus group as a whole, meaning that what was said is believed and agreed upon by all the Elders in the room. One exception occurred in an opening statement by one of the Elders, who requested that I record her as saying that not all those who went to Residential School had bad experiences. We accepted this as a group and carried on with the data collection. In keeping with community-based research, the Elders’ wishes were acknowledged.

The following outlines the Elders’ opinions on why First Nation youth are at risk and what recommendations they would like to suggest to health care providers, schools, parents, and anyone who cares about or comes into contact with First Nation youth in the prevention of HCV. There will be no traditional teaching and cultural practices published, such as healing ceremonies, as these are to be shared orally and are considered sacred.

The tone of the Elders’ focus group was one of humor and concern. Overall they were happy to participate in helping determine recommendations for the prevention of HCV in First Nation youth. It was difficult at times to hear the Elders as they would all speak at once, showing their enthusiasm and knowledge and wanting to contribute to the study. The following sections
outline the risks and fears the Elders perceive First Nation youth to be encountering today, as well as the lack of parent involvement with youth; the lack of role models for youth; and lastly, the youth’s lack of First Nation cultural experience.

*Society’s influence on risk taking among First Nation youth*

The Elders felt that the youth are especially at risk for behaviours that increase the risk of HCV because of the many external influences currently available to them, in particular: the accessibility of drugs, new drug paraphernalia and rituals; the influence of others, for example, drug pushers; and technology, such as television and video games.

The Elders identified the prestige of drugs and the tools necessary to consume the drugs as a primary influence. As one Elder describes, the new drug paraphernalia is something the Elders feel the youth are attracted to, and actually lure First Nation youth into using drugs, for example, “There is the introduction of new drug paraphernalia, like snorting” (EFG#1). The Elders also indicated that the youth are influenced by other people regarding drug-taking. One Elder shared stories about her own son and of valuable items gone missing, probably taken to sell for the purchase of drugs. She questions, “Why [were] my spoons disappearing and my knives? And uhm, that girl was in the house for about three months, and . . . she was bringing that cocaine and stuff, you know?” (EFG#1). The Elders also brought up the accessibility of drugs, “Some of our own people sell it” (EFG#1). Everyone in the room shook their heads agreeing how important it is to find out how accessible drugs were. I was asked to ask this of the youth and this question was then added to the questions for the youth interviews.

Another influence the Elders identified is technology, such as television, video games and music, that normalizes violence, leading to an acceptance of risky behaviour (EFG#1). The actual violence the youth experience as a daily reality in their lives that leads to them needing to
take drugs to numb their distress is discussed in greater detail in the section detailing the youth’s input. The following section outlines environmental factors identified by the Elders that tend to put the youth at risk for HCV-related behaviours.

Absence of supervision

The Elders felt the youth had too much freedom in their lives because of the lack of guardianship. One Elder states the youth are “free to do what they want because the parents are drinking” (EFG). The following outlines the absence of supervision of youth by either birth or foster parents.

According to the Elders, the absence of the parents occurs due to parents not focusing on their children because they are, “engrossed in partying and don’t know where their children are” (EFG). Another Elder adds that there is, “no discipline in the home and they are not cared for” (EFG). There is also a “lack of direction, no personal boundaries and poor parenting skills” (EFG). One Elder stresses that, “Parents are encouraging children to do nothing with their lives” (EFGI). This discussion brought about one of the questions the researcher was to ask the youth: “Where do First Nation youth fit in today?”

The overarching conclusion that arose from these observations regarding the absence of parents is that the parents have “no respect for the child” (EFG). In First Nation culture, beliefs and values, it is a gift to have children and this gift is to be respected. Since the parents are not participating as parents could, I decided to look at education of the parents and how this affects parenting.

Formative influence of the education of parents

Many First Nation people attended Residential School, while others attended community schools. The experiences vary in each school setting, but both had an effect on the generation
who have children today. The mainstream school system is described by the Elders as a “failing of family and education system; it is not helping with social issues” (EFG). This illustrates that the school system failed the parents, affecting the social and family relationships of their children, and leading the current generation of youth to engage in risk-taking. One Elder referred to all the systems that hinder First Nation people, for example, “the History of the Residential School, [the] justice system, and the welfare system” (EFG). In relation to parents being able to be a parent and not having the skills to be parents, one Elder comments, “What you don’t know you can’t teach” (EFG). Parenting skills was an important concern that the Elders felt was necessary to explore further.

*Parenting skills and colonization*

At the beginning of this chapter, I quoted an Elder who wished to underline her positive experience at Residential School. She asserts, “Nowadays people are blaming the alcoholism addiction on the people going to Residential Schools . . . [but] everything I learned in Residential Schools I taught my children and now my children are all working” (EFG). This comment is important because even though not all had the same positive experience it was important to note that some experiences had not been negative, and this was respected by the rest of the group. However, the rest of the group was able to freely discuss the concerns they have with the experience of Residential School and its impact on today’s generation. Most of the Elders were aware of the consequences of being “institutionalized in Residential Schools by the government,” (EFG) and how this affected the parents of the current youth and in turn their parenting skills. One Elder describes the consequences as a “lack of direction in regards to . . . personal boundaries. That we evolve, uhm, poor parenting skills” (EFG).
Another impact the Residential Schools had on the parents is the neglect of touching. The parents did not have personal contact with affection or love and when they left the Schools and had their own children, they were not able to show love and not able to show pride in their own children, not only because they did not know how, but because they were afraid of the child protection act that, while being rooted in well-meaning, potentially makes it a crime to hug your child: “youth protection of sex abuse [results in the parents] withdrawing from showing affection” (EFG).

One Elder narrated the history of First Nation people in Canada:

You know if you look at [it] how did this start? . . . Do we have to go back into our history and look at what has happened to our people? You know in ancient times we did have a healthy lifestyle. We had our laws and our spiritual laws and we had families and communities that worked together, that cared together, that supported one another and where there is good times and bad times. And then come along the . . . institution of the government and Residential Schools. We can’t deny what the Residential Schools has done to our people . . . I’ll talk about my own family . . . cause I look at my dad he was born in Prince Albert, Saskatchewan I believe; I call him Métis, but I don’t know, he may have been status Cree for all I know. There’s no records. So his parents died young and then he was given to his Aunt in Red River, and she couldn’t care for him, so she put him in Residential School . . . He came out of there, not like he really was [before he went in]! He hated my mother [because she’s] a full blooded Cree, married her anyway and had eight children. And he didn’t like being who he was, being a First Nations person, cause . . . he was taught to be ashamed of who he was as a person, as a tribal person. And he passed that on to his children! And so you can relate [this] classic example in my family to what happened to a lot of our people in Canada . . . They had their pride of being who they were and are beaten out of them and brainwashed! [They were taught] that our languages and our culture and traditions were heathen, that uh, they weren’t worth anything. And that’s how my mom and dad were . . . And now that I’m older and thinking back, he didn’t know like they did back in ancient times, and he didn’t have anyone to love him, to show him how to love in the Residential Schools. (EFG#1)

The Elders therefore realize how the Residential School and the public school system continues to affect the grandparents and parents of today’s youth, meaning that they have no parenting skills and are not able to be affectionate to their children because of today’s child protection act that scares First Nations people about hugging their children. This affects how they perceive who
they are as a people, having no pride in being First Nations, and this in turn affects their children. As it is the parents who are primarily responsible for being positive role models to their children, the Elders asked the question, "Where are the role models for today's youth?"

*Role models*

The Elders concluded that, "There are no positive role models for youth, therefore, they have no [First Nations] role models" (EFG). Instead, television characters act as role models and often teach youth to live risky lives. One Elder emphasizes, "TV is promoting the risk of going over the edge, with life threatening experiences, extreme risks" (EFG). The Elders' awareness of the lack of role models for the First Nation youth today signifies the need to explore this with the youth themselves. The youth responded in great detail to this question, and their input is discussed in the youth section. The Elders agreed that not only was there a lack of role models for the youth, but that they also lack the cultural experience of being First Nation.

*Lack of culture*

First Nations refer to the past seven generations that experienced colonization as "the missing generations." First Nations culture was disrupted, legislated so that First Nations people would not practice their culture, discriminated against, and forbidden to its people. Many are now trying to rehabilitate the culture; however, it is difficult for the youth to carry on the culture without even knowing or experiencing the culture. So the question arises, how can they expect to be First Nation without actually experiencing First Nation culture? The Elders agreed that the, "loss of knowledge of spiritual beliefs and ceremonies also puts the youth at risk. The youth have no faith, no correction, and a decrease in attendance at the ceremonies" (EFG).

Therefore, the Elders felt that learning the history of First Nation people's treatment in history was important to note when discussing why First Nation youth are at risk for diseases.
One Elder went into a long explanation of what is happening with the youth regarding culture, the youth’s perception of themselves as being alcoholics and not First Nation, youth disillusionment with Elders due to the Elders’ own problems with substance abuse, and youth responsibility for themselves:

I was just visiting some people at one of the strongest bands last night, and they were saying that, uhm, right now is a very vulnerable time for the youth, specifically in regards to, to uh, almost being shamed in regards to coming to participate in ceremonies because they don’t know anything about it! And so they say, they go like this, “I can’t participate in this because my father or my mother or my grandparents, uhm, told me not to,” and so, uhm, when you look at where they’re at in terms of numbers of how much youth we have on our reserves, and how much youth basically make up the population you kind of wonder about where do we fit in, in regards to trying to make some kind of a difference? Look at where they’re at! How do we bring them in, in terms of empowerment for themselves, to be able to take on some of that responsibility and be accountable about it too? Because in the same sense, I think they’re kind of like looking at us and saying, you know uhm, “You can’t tell us what not to do and what to do,” uhm, you’ve lived in your own [life] and many of you have become alcoholics and so we see you that way. (EFG#1)

Another Elder describes the history of First Nation peoples’ experience:

I just wanted to . . . follow up what you were saying in regards to clarification against that medical profession would see it one way [only addressing the physical aspects of the person/disease], in terms of blame and shame on First Nation People [because they are stereotyped as being prone to substance abuse]. But also there’s a historical aspect in terms of colonization, cultural genocide, oppression, I mean those are all factors that [are] key in regards to why people make decisions the way they do. So it still has to go back to that context to look at the bigger picture [holistic and historical] not just in terms of becoming physically infected but there [are] also the affective [consequences of] the historical aspect . . . Our people still have very strong feelings about what happened to our people and the land, in terms of our way of life, in terms of the loss of culture of language of spirituality of family of everything that was sacred to us, eh? So they would still get angry what that and say, ‘what the hell I don’t give a shit anyway, I’m going to go ahead and do this [risk-taking activity]. (EFG)

In contrast to the above quotes another Elder mentions that the First Nation youth are “hungry for the culture” (EFG). Another Elder agreed, “Our young ones and our young people are crying out for that . . . They are so hungry for that.” Another had similar input, “I have so many young ones wanting to learn native ways and the singing and the drumming.”
Effects on the youth

It is clear that the historical experiences of the grandparents and parents continue to affect today’s youth. This section describes the effects and connections to risky behaviours among First Nation youth.

The Elders agreed that in many cases the influence of grandparents’ and parents’ had a negative effect on self-esteem. They described how the youth are “discouraged and just don’t care.” The youth were alienated from their homes and family life. As a result, the elders felt the youth lacked a sense of pride. As one elder stated, “a lot of us...have lost that sense of pride in culture and who we are,” (EFG).

The environmental issues surrounding the youth affect their self-esteem, their pride in being First Nation, and the extent to which they care about themselves. This discussion generated a lot of ideas regarding prevention, and the following section describes the Elders’ recommendations.

Elders’ Prevention Suggestions for First Nation Youth

The Elders felt it was important for the youth to take responsibility for themselves by being accountable for their actions, learning about their culture of being First Nation, following their own beliefs rather than being influenced by others, and taking pride in who they are. The Elders commented on the youth’s attitude to self-responsibility and taking ownership for their actions:

Peer pressure, a lot of blindness that we are responsible for our own actions and our thoughts ... That is something that’s lacking for the youth right now, that I’ve noticed ... “I didn’t do it! They did it!” That’s all you ever hear. (EFG#1)

I asked the Elders how they recommended that I should ask the youth about responsibility and accountability, and one replied:
Well I think using the word ‘choices’, pointing out the choices that they have, leads into responsibility. One goes with the other, you can’t separate the two. And you know what I tell people when I’m working with them and they’re in pain and agony and they’re feeling very hopeless and not wanting to help themselves and not to do anything about it? I also inform them that this is not a practice run, this is life. You only have one life. And you’re not given a second chance and that if you want to live, it is up to you, you have your responsibility for your life and the choices you make. (EFG#1)

In other words, the Elders contended that choices the youth make are their own, and they must learn not to blame other factors such as peer pressure or life experiences. The Elders emphasized how important it is for the youth to cherish one gift—the gift of life.

The Elders perceive new diseases brought over by the new visitors, including viruses like HCV and HIV, as “man made sickness” (EFG). First Nation traditional storytelling kept alive the knowledge of the diseases that the First Nation people were accustomed to dealing with and that they used to be able to heal. Many of today’s diseases were “imported” by the colonizers, and are therefore perceived as man-made. The Elders felt it was important to educate the youth in this notion of man-made diseases, so that they can understand that there is currently no cure for them either in traditional First Nation healing methods or in the western scientific methods.

The Elders felt that it was important for prevention measures to include information on safe sex because there is a risk of contracting HCV during unprotected sex. “There’s still a lot of unprotected sex out there, which is [a] risk for HIV and STDs” (EFG). This is an urgent message, as, due to the sexual abuse often experienced by First Nations youth, “children are starting to have sex at the age of nine” (EFG).

Traditionally, First Nation healing methods are holistic in nature, while the western medical model only addresses the physical aspect of the person, usually via prescription drugs. The Elders felt that the health care system could help more in the prevention of HCV by providing, “holistic assessment . . . What I mean by that is involving the youth in terms of what
that assessment would look like. So what kind of questions you ask them would be very important in terms of being involved in prevention. What would that look like for them today? If they were going to say, “No I’m not going to get sick” then what are you going to do to prevent yourself from being sick? . . . Because the diagnostic tools that the medical model uses, I don’t think would work” (EFG#1). It was decided that an effective question to ask the youth was whether they would like to be assessed holistically when they approach the health care system.

Reclaiming of Culture and Related Beliefs and Values

The elders identified that one of the central problems facing today’s youth is the lack of a genuine experience of First Nation’s culture. The Elders felt that the feeling of belonging to their culture would help the youth in many ways, seen as fostering higher self-esteem to providing guidance on healthy behaviour. In order to give today’s youth a valid experience of their culture, the Elders felt it was important to identify key ceremonies that might be useful to the youth, as well as problematic issues such as “weekend medicine” people who practice First Nations culture and charge people to participate in which may put youth at risk for abuse.

The Elders named several ceremonies that are relevant to the predicament of today’s youth. First Nation people in the past had names given to them at different times of their lives that were earned through correct behaviour. Some communities also had Spirit names, something one of the Elders felt strongly that the youth need. The Spirit name represents self-responsibility, and it is recognized that a certain amount of respectful protocol is necessary to receive the name, protocol that mainly features self-respect and respect for others. One Elder also noted that First Nation youth need to “cleanse their spirit” (EFG), as this represents a new beginning. Ceremonies of this sort include sweat lodges, smudging, pipe ceremonies, and other traditions that differ from Nation to Nation.
The Elders cautioned there are weekend medicine people practicing in the community who are not true role models, and that proper protocol needs to be learned and practiced regularly (EFG). Unfortunately, the cycle of abuse continues when those who have not healed from their hurts transfer the abuse onto others. For example, sexual abuse, physical abuse, and emotional abuse may occur because of the unhealthy Elders who may be practicing bad medicine on others.

The Elders wanted to include ceremonies that involve blood-to-blood contact in the prevention section as there needs to be education around this and the risk of HCV. For example, “Ritual cuttings, things like . . . piercings . . . blood-brothers, blood-sister . . . type of things” (EFG). These ceremonies are putting youth at risk for HCV because there is the sharing of the ceremonial tools.

The Elders feel strongly that culture has an important role to play in prevention. The protocols that must be followed demand self-responsibility and respect for others. With respect comes the responsibility of knowing what your First Nation cultural practices are and the dedication and commitment to following them. It is also important to note that some people practicing the culture may not be respectful and therefore are not considered Elders. The Elders cautioned the youth to be careful who they choose as Elders, as they should be well-known or recommended by others.

*Education about HCV*

The Elders were very concerned about the wellness of the First Nation youth. They were also interested in learning about HCV and had many questions. The Elders feel that everyone needs to learn what HCV is, and that the children should be taught the awareness of HCV in schools. During the focus group, one Elder stated, “You got to get them when they’re young and
in the schools. I would include the families; you can’t just educate one!” (EFG). Another Elder in the group suggested “educating Elders that are involved in spiritual and healing work. They’re not all up to par in terms of diseases, and so that needs to take place” (EFG).

In the discussion, it emerged that the Elders also felt it was important to educate the medical system and its doctors regarding the needs and beliefs of First Nations people. They perceive doctors as not only having the feeling they are above everyone else, but also that doctors are entrenched in the physical, medical model of health care, dealing with one disease at a time as opposed to addressing root causes in the holistic way traditional to First Nations. One Elder explains:

They’re . . . so high on themselves that they’ve got all this education, they [think they] don’t need that piddly education [about First Nations emphasis on the holistic aspects]! That’s the real difficult part in terms of the medical model, is that it’s so closed in terms of the diseases they become compartmentalized into a little box, so we have a box for hepatitis C, we have a box for AIDS, we have a box for cancer, we have a box for heart disease. (EFG#1)

The Elders’ opinion on how to educate the youth as well as the medical system on First Nation youth issues, and what to include in the education about HCV, includes remarks such as, “with as much activity and as much open learning experience as possible in regards to not only talking about this disease itself but also in terms of including things that pertain to healing and culture” (EFG).

Examples of how to educate the youth were provided, such as “the drumming, . . . the games that you talk about to bring them in and to say how can we turn this into a fun kind of experience for them, instead of one that’s down and out and black and depressed” (EFG). One added, “Don’t talk about the disease!” (EFG). This demonstrates the perception that First Nation cultural practices can proactively prevent diseases such as HCV by emphasis on the culture being about self-responsibility and respect for self and others, referred to by one Elder as “wellness
activities” (EFG). This method of prevention is referred to in health textbooks as ‘health promotion’. The Ottawa Charter defines health promotion, in part, as “the process of enabling people to increase control over, and to improve their health. To reach a state of complete physical, mental and social well-being” (Shah, 2003).

Another Elder added that incorporating cultural teachings into preventive education for HCV means that the education would not take the form of a one-time workshop, but would be more like the movie Training Day, in which training is very thorough and repetitive. “It has to be ... the holistic model and the medicinal model ... let them learn from that ... this has to be ongoing; it can’t be a one time thing. It has to be ongoing like Training Day, young people training the parents to help themselves and to help each other” (EFG).

We concluded that it is important to include all ages of First Nation people in the education of HCV, so that everyone can help each other. The Elders also said that effective HCV education would therefore include First Nation cultural activities, not focusing solely on HCV itself, but addressing the concepts of self-responsibility, which includes respecting self and others. Educating the medical model providers on holistic assessment was also selected for attention as the Elders felt they failed to provide this service.

Summary

Being responsible for self, ensuring the medical model is able to assess youth holistically, and providing health promotion a well as cultural activities in the education of HCV was important to the Elders in order that prevention of HCV is realized. The following Elder quote on personal choice and non-blaming of others sums up the potential effectiveness of prevention through objectively considering the situation, “One of the biggest things we have is we have a choice, we can choose whether we want to keep on this path that we’re going. If it’s a destructive
path and we know where it’ll end up? And uhm, all of the other way and going towards a health lifestyle. And also the sense of responsibility! I don’t think that’s taught enough, you know. We are responsible for what we think, what we say, what we do, our actions, and the decisions we make through all ages and stages . . . We are responsible for what we say and think and do.”

Having explored the Elders’ opinions on HCV, risky behaviours and prevention, I then carried out my interviews with the youth. The following sections describe the First Nation youth’s conclusions, and the resultant themes of risk and prevention.

_Setting the Stage: The Emotional Lives of First Nation Youth at Risk_

Before I begin to discuss the emerging themes that came about from the study, I set the stage by sharing the emotions and overall tone of the interviews with youth focus group and individual. The focus group interviews took place at facilities, and the participants were pre-selected based on convenience of the facility (time and space availability), and the youth’s choice to participate. The focus group and individual interviews took on different characteristics. In the focus group interviews the youth seemed to take on a “follow the leader” approach to providing information. When one youth spoke, the rest would follow, seeming to almost need permission to share their information. The emotions that arose from the focus groups on why youth take risks were more upbeat as they described the “fun” and “rush” of risk-taking. On contrast it was during the individual interviews that the youth seemed most at ease and provided information freely. All the interviews provided rich data with the exception of one. This particular participant had not yet experienced being at risk for HCV, attended school regularly and lives with both parents. The data she provided consisted of short answers or simply “I don’t know,” (FNII#10). She was very quiet and shy, and to get as much information as I was able took much probing.
The overarching emotions that emerged from the individual interviews were feelings of anger, sadness and rejection. The youth were often uncertain and needed assurance that what they were sharing was relevant. The following two quotes express how the youth felt they were treated in school. One male youth aged 17 explains how he felt emotionally when being called names in school and how he dealt with this situation physically:

When I was younger . . . I was like one of the only native kids in the whole school. So everybody would make fun of me. They called me a nigger but I wasn’t even a nigger, so I would just get mad anyway and start fighting and stuff. That was like in grade two, three, four. (FNG#4d)

The youth described being bullied in school and how one female dealt with this involving her parents and through her art work:

They can express themselves like art and everything right? And you can express yourself in a whole bunch of different ways, like we have our dancing right? I used to do that. When I was upset I would start drawing. My grandparents kind of figured out I was upset sometimes [because] I’d have like a dragon trying to burn down a village and with a thunderstorm behind it. And they kind of figured that I’d be pretty upset about something. And so they’d ask me what was wrong and then, I’d tell them I was getting bullied at school. (FNG#1a)

The youth expressed many emotions throughout the focus group and interviews, from seeing risk-taking as fun and enjoying the rush of doing drugs, to being angry at what they experience in their daily lives.

The body language within the focus group interviews with the youth was diverse. At times, the youth were very relaxed, lying over couches, sitting on the floor, eating while participating, and freely providing information to the interviewer. At other times, the youth’s body language was of discomfort. One youth in a focus group kept very quiet and in the back and added information very quietly. While in the individual interviews, shyness prevailed for the beginning of the interview as comfort set in, the youth were able to freely provide information. The seating arrangements allowed for the youth to face the interviewer or to look in other
directions for comfort and safety. Other body language observed was of the youth looking in other directions and not directly to the interviewer. There was usually something in the youth’s hands to fidget with when they felt uncomfortable with the topics at hand.

My own personal emotions that came about from interviewing and providing the focus groups were very oppressive. I became depressed and very saddened after each. Even though I already knew that the experiences the youth shared are common, hearing it from their mouths was very hurtful. This made it difficult for me to continue the work, as I felt I needed breaks between interviews and writing.

Emerging Themes

The major themes that emerged from the data include: surviving risky lives; in search of positive role models; being a First Nation youth means taking risk; being a member of a culture whose traditions have been eclipsed by violence, drugs and alcohol; access to health care; and awareness of HCV.

Surviving Risky Lives

Five sub-themes emerged from the youth’s experience of surviving risky lives. They include: a) Growing Up at Risk = The Normalization of Risk; b) Progression of Risk Taking; c) Accessing Alcohol and Drugs; d) Reasons for Risk Taking and; and e) Towards Risk Prevention.

Growing up at risk = The normalization of risk

Both youth and Elders pointed out that the conflicted environment results in First Nations youth growing up at risk. As a result risk becomes normalized, creating an everyday reality that normalizes the image of First Nations people as alcoholics and drug addicts:

Usually we [First Nations] don’t grow up into the very good neighborly environment . . . It’s just you’re in the downtown area; it’s just what’s around you. It’s what you’re
exposed to throughout your life. You walk outside and you look around you and see people doing drugs and stuff and one day you decide to try it and easier to face coke than it is to face your problems in the past. (YDC#2a)

The youth described how drugs are one of the normal activities in one's life. When asked why adults find it difficult to care for their children and easy to use alcohol and drugs, the youth replied, “Because they’ve probably smoked weed their whole life and it’s probably one of their major surroundings” (FNII#6). The environment of being exposed to alcohol and drugs is familiar to many of the youth: “I think it’s pretty much based on the kind of environment you grew up with as a child and what you were exposed to. If you were exposed to a lot of drugs and alcohol, it would certainly affect you in the future. Especially with parents, you see parents sort of do it, and you see your dad drink or whatever and you grow up, it could have long term effects” (YDC#13). The youth also explain how they did not have a choice when it came to attending parties with parents, as one verbalizes: “Ever since I was a kid I was at parties with my parents, always asking them to go home, and they’d be like, “Oh, one more hour, one more hour, or something”” (FNG#1a). Many of the youth who witnessed friends whose parents were not always there for their children emphasizes, “All of my friends who started doing drugs, they had really neglect[ful] parents. Like they hardly ever see them” (FNII#11).

Their experiences are so consistent that the youth begin to use stereotyping, as one explains:

From my view, it’s sort of the majority of them, from what I’ve seen . . . It’s like you look out on the streets and you see mostly like, the majority, First Nation people sort of doing drugs and wobbling out of bars drunk and stuff. It’s sort of the majority. (FNG#4d)

One Elder described the youth’s beginning stages of risk-taking like this: “[youth are] free to do what they want because parents are drinking” (EFG#1). Problems begin at a very young age; the youth I interviewed were all between the ages of 13 – 17, yet, as one shares: “My little brother he
lives . . . in the smaller town and all he does is smoke weed . . . He might drink once out of every two months or something, usually when I offer him some. He’s fourteen” (FG#4d).

In recounting their experience with witnessing violence or experiencing violence as a youth, one youth describes instead witnessing parents as alcoholics and addicted to drugs, “My dad was an alcoholic and my mom was just a drug addict, but I was never exposed to violence” (YDC#12). Another youth tells a different story, “My dad used to rough up my mom sometimes, and I use to see it. Yeah, it hurt. Yeah, I don’t want to be like my dad. Or what he used to be. But they’re better now. Yeah, it’s just that, it’s still in my mind. I used to see it when I was little and I can’t get it out of there” (YDC#13). One of the female youth responded by sharing information on her parent’s behavior when they would come home drunk:

My dad, every time he’d be out partying with my mom, I’d always be at home with babysitters and they would come back and they’d be like...I could tell they’re drunk, and I’d be like, what’s the matter with you guys? And then we’d have a big long talk, and they’d be like don’t ever do this [meaning get drunk]. I just always felt they were getting mad at me for no reason . . . They’d yell, right . . . I’d be like okay, sorry, I didn’t mean to do anything, I didn’t even try it [alcohol] . . . They always said if I ever did anything they would kick my ass or something. (FNG1a)

The youth explain that the opposite situation also occurs; that some sober parents may not even know their children are doing drugs: “There still are some kids that the parents are . . . really cautious and stuff and watching them all the time, but they just keep in on the low and stuff. Some parents don’t even know when their kids are doing drugs. Yeah, they hide it” (FG1#3c).

Talking to the youth revealed that being at risk has its roots in the way parents or guardians raise their children. The lack of success of the guardians or parents sometimes causes them to set goals in keeping with their own problematic life experience, thus putting youth at risk. Parent’s low self-esteem also affected the youth and this was passed on down to them as
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youth, one participant describes how her parent’s low self-esteem was passed on down to her and how people learn to continue this cycle:

I guess low self-esteem always starts with somebody else. Somebody else having low self esteem on themselves so they pass it out and you know, say ‘Oh you’re not going to succeed in life’ because maybe they haven’t succeeded in life. Or you know, you’re just stupid and you know you’re going to be just like this other person. Like, a lot of people used to put on them like you know; your sister’s stupid, so you’re stupid too. Or you’re mother’s stupid so you’re stupid. (FNII#5)

A similar story, but one that involves physical abuse was shared by another youth:

Yeah when I was younger she used to hit me cause, I don’t know, I used to stay out for long periods of time and she knew my friends were there doing that [drug-taking]. And she use to give me lickings cause she thought I was high or whatever, and I wasn’t high. (FNII#6)

Passing on the learned behaviors of verbal and physical abuse and neglect to the next generation was described by one youth, who stated, “You grew up with it and then you pass it on” (FNII#5). One youth summed up why First Nation youth take risk, “I don’t know, like uhm, maybe their brother or uncle went to jail or something, or maybe they just broke up with a boyfriend or girlfriend, or they had an argument with their parents or something” (FNII#11).

The First Nation youth I talked with during this study have so much disruption happening in their lives that most of them have not had the experience of what today’s society would consider a normal life, and it seems likely that this is the case for the majority of their peers. It is also important to remember what Brentro, Brokenleg and Van Bockern (1990) stated about how the youth felt as, “alienated,” “troubled” and “difficult. The youth interviews demonstrated these three by showing these through their emotions and words they used during their interviews.

With these feelings of being alienated, troubled by their parent’s behavior and the way elder’s feel the youth being as difficult, makes the youth want to risk-take even more.
Progression of risk taking

The progression of risk-taking into more and more dangerous territory as described by the youth participants can start from something as simple as not listening to your guardians, or something as consequential as going to jail. One youth expresses what happens when she does not follow the rules of her guardians that cover being responsible by going to bed at a reasonable time, to eating less junk food and more healthy foods, and avoiding the risk of getting in trouble. She identifies her early risk-taking in this way:

I go to bed at a reasonable time, I eat properly, and I don’t just fix out on junk food like I would’ve. Uhm and I...yeah, I have to be in by...nine and my grandparent’s rules, be in by dark at least. Or if I’m with a group of really good friends and my grandparents trust them then they’ll let me hang out a little bit longer but as long as I’m in, within hearing distance...like a lot of stuff has been happening around my neighborhood lately. So...Sometimes...and sometimes...sometimes I’m just being an idiot. I get into BIIIIG trouble. I thought it would be fun. It was fun while it lasted and then...Yeah, whatever reaction you do there’s always a consequence. (FNII#5)

Youth shared information on when they started experimenting with drugs and alcohol to the progression, or of not progressing, to harder drugs. In previous statements in this section, youth illustrate that drugs and alcohol are everywhere. One youth explains how one might get addicted and in debt to drug dealers, “Depends on what drug, the dope dealer might want to get you addicted and hooked and start taxing you cause you’re in debt” (YDC#15). Developing debt to the dope dealers provided circumstances for the youth to pay their debts by becoming drug dealers and/or by resorting to prostitution. One of the gender differences expressed by one of the male participants explains, “The girls can go into prostitution and stuff... while the guys turn to crime, and steal cars, [doing] car-jacks, B and E’s, to support their habit or support what they haven’t paid back” (YDC#14). When asked about the gender difference in risk-taking, one female answered:
Yeah, I feel females take a lot of different... there are some males out there that take risk with uhm, like sexual activities and stuff. And I guess a lot of them do that... but a lot of the female take it more for them... with the sexual activity cause [selling their bodies], like, them being abused... or not respecting themselves or not feeling like anyone respects them. Points them into that direction, like they’re trying to just get love from anybody they can get love from (FNI#5).

When asked about the choices they make regarding protecting themselves, they usually talk about harm reduction strategies, without using the words harm reduction, as one youth explains:

Doing more, different kinds of drugs every... like I started off just smoking, and then smoking weed, and then drinking, and then drinking to like pills and then I don’t know. From that I did like crack before I ever did mushrooms or acid. Then I did mushrooms, acid, ecstasy and morphine and shit like that. Just whacked out drugs... speed. But now I slowed down, I only did that for probably about a straight year, and now it’s just pretty much alcohol and weed. (FNG#4d)

The elder’s wanted to know what the difference was between risk-taking of drugs and alcohol to risky (dangerous) sports. An example of one youth’s explanation between risk-taking in risky sports and risky drug taking like this:

Drugs are a different thing cause uh, say uh, you realize say uhm you realize with skateboarding you’re falling and your starting to hurt yourself too much and it’s starting affect your physical wellbeing and possibly mental wellbeing as opposed to doing drugs. If you’re doing drugs and you’re getting into a real mess and stuff and you get scabies and all that and scabs and all that, it just doesn’t faze you, you continue to go forth with the drug; the whole drug economy. (YDC#15)

Youth talk about hanging out with the wrong kind of friends and how this leads to doing drugs and to the addiction of drugs:

I always wanted to be on my own, because I was always stuck in the house where I was always, it was like a jail house to me, ... where I always went out with the family. And basically where I over took that and just kept on going out and doing my own thing and when I did that I hooked up with the wrong type of people that did this kind of stuff and basically got myself hooked on it. (FNII#8)

Access to alcohol and drugs

According to the youth, access to alcohol and drugs is a major factor in risky behaviour because it is so easy. “Like you can just go out and ask someone, and say can you buy me some
liquor and they'd be like yeah, and they'd buy it for you” (YDC#14). The youth also talk about how easy it is to access drugs and alcohol, “I mean, there are so many people that sell drugs and you know they're there, and you just go there [where the drugs are]. Most of the time, you don't even have to ask, people just ask you...if you need this, if you need that” (YDC#14). One youth states, that “my belief to that is when they hit the ages between 12 to 15 is when they start having these drugs and alcohol get in their lives because they hit that age where they get into high school. Where the older youth like grade twelve’s like to try and pressurize the younger ones to buy and stuff like that” (FNII#8). One youth, mentioned earlier as a participant who returned of his own accord the day after the interview with written answers to the questions, shares his thoughts on how youth might access alcohol and drugs, “At teenage sometime that’s when they get taken advantage of to lowir [lower] them in to it. By older teen that the yonger [younger] one looks up to” (FNII#8). The youth alludes to the idea that older teens who are looked up to as role models lure younger youth into drugs and alcohol by taking advantage of them as well as lowering them into using. Lowering them into it means, to me personally, that someone who thinks they are above you makes you feel you are below them in stature. His writing illustrates that this youth’s academic skills are not at the level expected of a 17 year old.

Access to hard drugs seems to differ from community to community. One youth tells of his own community experience with drugs, “North Van is way different than Vancouver, right? And it’s way more calm over there, but people do hard drugs over there. I know a couple of people that smoke crack and everything, but most of the younger natives usually drink more and smoke pot than do other hard drugs” (YDC#13).
Reasons for Risk Taking

There are many sub-themes that emerge from why youth are risk-taking, such as:
Reasoning themselves into thinking it’s OK; feeling that it’s cool; perceiving having money as cool; having a bad history; not caring about themselves; following people due to peer pressure; the importance of having connections and friends; and having no support.

The reasoning the youth often seem to use that leads to the acceptance of using alcohol and drugs is that they see many people who are using and yet are still alive. As one youth explains, “Yeah, because it’s not bad right? Or they don’t think it’s bad. Well they know it’s bad, but they don’t think something wrong because they’re still alive” (FNG1#3c).

When asked about the need to fit in as an impetus for risky behaviour, some of the youth described the attraction of having connections and money: “If you got money you’re cool!” (FNG#4d). I asked for clarification on what ‘cool’ was to the youth and he described it as, “Being down. Like everyone’s doing it so you have to do it too” (YDC#15). Another youth who uses the word ‘cool’ in his language about why First Nation youth take risk says, “Because, uhh, you see other people doing it and you want to be cool and do it like them, or like you just don’t want to face reality and you want to get away from it all and start doing drugs” (YDC#14). A female participant expressed her reasons why First Nation youth take risks, “For tattoos, I think they just want to do that to be cool, cause they see their other friends having tattoos. Same as with the drugs and alcohol” (FNII#10).

The subject of purposeful risk-taking elicited a variety of responses from the youth. One youth describes how youth use drugs to numb the pain: “Do it on purpose right? Maybe to make themselves feel better when they grew up and they’re hurt, but it only numbs the pain it doesn’t fix it” (FNG#2b). Similarly another youth stated, “Well I don’t think it’s cause of peer pressure. I
think it was cause they want to get rid of stuff from when they were little or something. Like if they had a bad history and they just want to get rid of it through drugs and alcohol” (YDC#14).

On the same topic of bad life experiences, one youth claims, “Because something bad happened to them. Like, uhm, Residential Schools, for my grandpa and for a lot of my other grandparents and a lot of other people, so it’s still happening, still abuse is happening in the family” (FNII#5).

In relation to the mind, body, and spirit of a person one youth expresses what happens and why youth risk-take:

> I think the mind takes a lot of what the spirit is. Cause a lot of youth physically don’t care about themselves physically. And uhm, but with the mind and the spirit I think when it takes over and it blocks their problems, it also blocks their spirit. Their spirit is not who they are, and uh, when they’re all high it’s not who they are cause they’re not the same. Like they could be a really happy person, but when they get high they could turn into a real angry person. Like, so I think when you’re doing drugs it just makes your mind worse, like it kinda blocks something. It just piles more into your bottle. So, then it makes it worse when you feel like you need to get it out . . . I think cause they don’t know right away. Like right away, like they . . . it blocks a lot of their problems. But when you’re sober and you can’t get those drugs, you think about where your life is or what’s happened to you in your life, and you think even more about it because you haven’t thought about it in a long time. (FNII#9)

The youth added another reason why youth risk-take. For example, they abuse themselves by risk-taking as if they cease to care about self: “Well because nowadays I think people don’t care as much as back then about what these drugs are like and these diseases that get caused by these things. Back then they used to care a lot more. But now the youth aren’t as caring as much and aren’t as respectful as others are” (FNII#8).

The themes that emerged from discussions with the youth about reasons for risk-taking, included needing to have friends; peer pressure; needing connections; and following people, offered fruitful explanations about who is at risk and why. Peer pressure, which on the flipside is sometimes used by health care providers in the prevention of disease and even by some of the youth, was described by some of the youth participants as ‘following people’. When asked why
First Nations youth take risk, one youth spoke of peer pressure as always being a part of his life, “I don’t know, I’ve never grew up in a life like that [without peer pressure]” (FNG#3c). When asked about what peer pressure consisted of, one described the percentage of youth who were likely to fall prey to peer pressure:

I guess about half of them, more than half of them wouldn’t be doing drugs or anything if there was no peer pressure. But then there’s also a little bit of percentage that will, that will do it on their own . . . They think it might be cool . . . like everybody’s doing it and they want to . . . Yeah, like they’ll follow it, they’ll follow people. (FYII#5)

One youth described peer pressure as something that “makes them make decisions they don’t want to” (YD#12). Another youth also framed peer pressure as something bad: “Bad word . . . [it’s] when you ask somebody to do drugs, do drugs, and they keep asking and you to do it” (FNII#10). On the other hand, some youth understood the need to belong “I think they just want to be part of a crew or something” (YD#12). One youth, after a long period of silence, states:

I always thought about that [diseases like HCV] with myself too, but like when you’re in the action and you’re there and you’re doing it, like you can always do workshops on it. Like I’ve always done a lot of workshops on Hepatitis A, B, and C and the whole how A is different from B and B is different from C and how it goes on, and it’s when you learn about it, it’s like okay, I don’t want to do that, but then, when you’re there with your friends and I guess a lot of it comes from peer pressure on each other. You know like ‘here you go’ you know and you just like, totally forget and okay whatever my friends doing it I’m gong to do it too. So it’s a lot of peer pressure and forgetting what you learned before. (FNII#5)

Following this, another youth spoke of connections in the following way:

No, if you got money then you can chill right? And if you know the person, a friend of a friend you can hang out and, or uhm, if, uh, you got lots of connections with people. Yeah! It’s actually more about connections than money! I don’t think it’s about clothes. You could be the biggest geek in the world, but if you got connections and money then it’s fine. It’s mostly about money, isn’t it? (FNG1a)

On the same topic of having connections, but this time in the positive sense of support one female suggests:
I guess right now today, a lot of the youth are into like, the violence and the drugs. But I think a lot of the youth are smartening up but they don’t know how to get out of that. Like they don’t got that much support to like be able to go to school and be a doctor. And they don’t know what to do so they just turn to the violence and drugs or alcohol because they don’t know how they’re going to be able to be a better person and get up there because they have no support . . . Yeah, I think it’s easier to turn to drugs and alcohol cause it’s always there. It’s always out there and you can just grab it, it’s not like grabbing a book and putting your mind to it, and finishing the book. When here all you have to do, is take a drink like it’s a cup of juice or something right? (FNII#5)

Many factors draw in youth to risk-take, for examples, some of the risk-taking is fun and being in the environment of someone who is doing drugs. Some youth talked about the fact that risk-taking is fun and advised people not to forget that the youth actually want to get high. With a highly charged excitement, one youth expressed “Yeah, its fun, its fun . . . like you know when you play soccer or something. Its fun right? And when they sell weed, its fun! Sometimes it does make them feel good, some people can say that it doesn’t make them feel good . . . but it does right?” (FNG2b). When in the environment of people doing drugs, it is difficult not to want to do it as well as one youth affirms, “I don’t know when people are getting high on something like crack or something, I guess it just makes the other person want to get high too I guess. And then I guess they can get so feigned out that they probably will use a needle, or the needle that everybody else is using or something. Or the pipe that everybody is using or something” (FG#4d). In the same focus group setting, one youth describes doing drugs as being like a sport. Another youth describes the actions he takes to fit in and how it feels good: “Well I do smash and grabs for liquor, and that’s pretty much all I do, and I steal cars for the rush” (YDC#4d).

I asked the youth about ‘fitting in’ and whether they put themselves at risk to fit in, and they responded with, “Yeah. That’s pretty much it, yeah” (YDC# 12). Connections emerged between fitting in and trust during a discussion on sharing drugs and drug paraphernalia. “It’s just like someone is like…what, you think I got a disease or something? And then I guess, they
might just get into an argument, and then I guess they’d be like, oh I guess you don’t, eh? . . . and then they just do that [share drug equipment]” (FNG#4d). This narrative suggests that the youth require trust from each other, and that providing this trust through the sharing of equipment puts them at risk for HCV.

Gender differences in risk-taking did not seem to be a major issue. However, three of the youth made noteworthy statements regarding the differences in gender risk-taking. One youth describes the differences between males’ and females’ risk:

There are some males out there that take risk with, uhm, like sexual activities and stuff. And I guess a lot of them do that . . . but a lot of the females take it more for them . . . the sexual activity, cause, like, them being abused . . . or not respecting themselves or not feeling like anyone respects them points them into that direction, like they’re trying to just get love from anybody they can get love from. (FNII#5)

While one male feels the girls are at higher risk, another points to male peer pressure as a significant factor: “I think guys are at higher risk . . . Well we, well when you’re in a group with guys right, and everybody says, everybody’s doing heroin right? Mostly guys would want to be fit in, be one of the cool guys and they do it right?” (YDC#13). According to the youth the girls are looking for love from anybody and the guys take risk to fit in mostly. In the same focus group two of the youth expand on the issue of how low self-esteem places girls at risk by stating: “Once a boy breaks up with them, they get depressed and they look for some solutions for their problems. They just end up doing drugs” (YDC#14).

It transpires that it is not only the youth trying to fit in with others that drives drug-taking. One female indicates how and why she encourages another girl to use drugs, and how she controls that person’s behavior with the use of drugs in order to deter behavior that does not fit in with her group:

I have a friend and she like really didn’t, I guess she didn’t fit in like lots of girls and we used to pick on her, but she used to hang out with us all the time even though we picked
on her. And then . . . she'd start smoking weed, and then people started to like her more, and it's like . . . I don't know why. But then she used to get really annoying and then some people would give her weed and then she'd be normal [more like the other youth]. I guess she really wouldn't say anything when she was high; she would just kind of sit there and like, I don't know, just sit there and like be quiet. That's why we used to give it to her, she used to talk so much. (FNG#1a)

One youth describes how another girl did not want to do the drugs on her own, so she convinced others to join her, "You might have a friend come up to you and say hey, I wanna try crack, can you try it with me? Cause they don't want to do it by themselves" (FNII#11). She goes on to explain that, "From what I've witnessed, about half of them say yes" (FNG#11).

Youth Initiating Risk-Reduction/Prevention

Several interesting examples were given of youth practicing risk reduction and preventive behaviour of their own volition. One youth spoke of his decision not to progress to harder drugs, deciding to buy a pack of cigarettes instead of drugs. Another youth showed similar resistance explaining what he would do with $10, "Yeah if I got ten bucks in my pocket . . . I'd go buy a joint or maybe, or maybe . . . most likely I'd buy a pack of smokes" (YDC#13). The described preventive action that youth can be taken if they are engaging in risky behaviours, for instance "By not injecting, and if you're going to hit the pipe . . . use your own pipe or wait till it cools down and wipe the end off [HCV can be passed on via crack pipes due to the heat of pipe cracking lip skin and causing bleeding] . . . Or maybe just buy your own pipe and don't let anyone use it . . . or buy your own needles" (FNG#4d). A female discussed her techniques for protecting herself:

I'm really aware of what I do, and I'm smart, I don't just go out . . . like depending on if it's a Friday and I'm going to go party right? I always make sure I have my cell phone with me right? And I always tell my mom honestly that I'm going to go party tonight and I'm going to breach my curfew, whatever . . . and I tell her that if I call her, that means I'm safe right? (FG#1a)
When asked about choosing paths, one youth expresses that both the healthy path of self-responsibility and respect for others (the Red Road) and the dangerous path of self-destruction and self-abuse (the Black Road) can be adopted by youth, at least for a while: “Kids take a bit of both of those I guess. You can . . . smoke pot and go to school . . . You can drink on the weekends and still do your homework and everything, still go to school, get a job” (YDC#15).

*What Deters youth from Risk Taking*

Findings from the youth interviews revealed specific instances that caused them to reduce risk-taking behaviour. These included witnessing others getting very sick, and feelings of remorse at hurting those who show affection to them or love them, or who had been significant to them in the past, including those who had acted as authority figures or who meted out ‘tough love’. An example of tough love is when a guardian asks the youth to stay at home instead of partying, or they will get kicked out of the house.

Youth were deterred from risk-taking by witnessing loved ones who live unhealthy lives. For example, one youth emphasizes, “My mom’s a drug addict and stuff and my dad’s an alcoholic, but I’d sort of use my mom and stuff I’d seen her go through to sort of stop me from doing harder drugs and stuff like that. Just like realizing what I would fall into from my mom. What has happened to her and what she’s gone through, I’d just sort of look at that. And that sort of scared me away from whatever it may be that may come along one day” (YDC#15). Similarly, a deterrent to using needles was described by one of the youth: “My mom’s a heroin junkie, so I just don’t want to end up like her” (YDC#12). Another youth expressed the same concern about ending up like other people, as well as being put off by the drug paraphernalia itself: “I just don’t like needles…No, and I see what it turns people into” (YDC#15).
Youth reported feeling remorseful when they had participated in risk-taking activities, and realized that this is what their parents or guardians were trying to warn them about. Remorse sets in usually after a crisis or when the youth are able to see the hurt their actions are causing to their loved ones. As one female put it, “I could see everybody around me was suffering cause of what I put them through with my drinking” (FNII#11). Youth whose parents have HCV describe how they are taking care of themselves once diagnosed with HCV, “she started taking care of herself after a crisis situation occurred in her life, “A tragic thing happened so . . . that’s when she did change her life” (FNII#9).

In Search of Positive Role Models: Someone’s Footsteps to Follow

Role models are important to the youth. Being young and having someone to follow is important if the youth are to have any kind of a future. Two different kinds of role models emerged from the conversations with youth: healthy ones, who live their lives as positively as possible, and those who they learned from as regards what not to do with their lives, for instance, people who had progressed to harder drugs. One youth shares her ideas on the courage of First Nations youth, and how it can sometimes be used in the wrong way:

Well, not all youth have courage. That’s where a lot of it, peer pressure comes into it cause, when you don’t have a role model or you don’t have a person there to support you, you don’t want to do something, there’s nothing you could really say for yourself cause you’re not strong enough. But those people that do have a lot of courage maybe use it in the wrong way. Cause if they empower themselves, so they can tell somebody you know, it’s cool and la la la…and that’s how they get the people who don’t have so much courage into that kind of life style. (FNII#9).

One youth explains how role models need to be consistently present to be effective. After a very long hesitation, she states, “I had a few, but they weren’t…I’d seen them maybe once a year or something…so it was kind of hard to follow their footsteps” (FNG#5). The most negative role models are ones that are consistently present and modeling the risk-taking behaviours, such
as one youth expresses, “Yeah, cause I grew up with, uh, around that. My mom and dad are alcoholics and they were doing drugs all the time” (YDC#12). Another youth shares a similar experience, with an emphasis on the unavailability of authority figures involved in substance abuse, “Or it’s just like where your father or mother gets lost in their world still like, they’re still drinking or still drugging or whatever it’s called. That’s why they’re not part of your life” (FNI#9).

One youth talked about how First Nation youth need someone positive to look up to. The following quote is taken from Appendix V; the handwritten answers the youth gave me when he returned the next day of his own accord. This youth lives in a foster home and has never lived or experienced his First Nation culture. He states, “They should have somebody pousidtav [positive] to look up to so they could talk to them,” (FNII#8).

One youth who lives in a foster home explains his idea about living in an environment of affection or caring and how this might affect youth practicing risk-prevention:

Yes, that would [cause youth to think about prevention] to some people but not to all because sometimes kids have that attitude of just saying, Who cares? And they don’t show that respect back to a family member where they basically just don’t care about themselves cause of what they [guardians/parents] do sometimes. Some other kids see that and it sometimes takes a while to basically get off of what they’re doing and continue on with their life without doing drugs and alcohol. (FNII#8)

Some First Nation people have difficulty discussing their true feelings unless they are under the influence of drugs and alcohol. Since drugs and alcohol help a person be brave, one of the youth discusses her father’s courage to talk, who does not deal with his issues unless he’s drunk, and how she tries to talk to her dad at those times, thereby learning from him how to deal with her issues as well. She explains, “Yeah, like he doesn’t know how to…my dad he doesn’t know how to deal with his pain. He doesn’t like talking about it at all; my dad won’t talk about anything
about his pain, right? Unless he’s drunk, then he’ll start talking about it, right...and that’s usually how I try [drunk as well] to talk to my dad about it” (FNG1a).

It was interesting to learn from the youth what constitutes a role model for them. Having money was a sign of social status that youth who have experienced being responsible for their own survival, for example, through selling drugs, look up to, “You look up to people you can go to or...Well all the people that are straight and know about drugs, NO!...and, well, actually I look up to people that are rich and make money,” (FNG#1a). Another youth concurs, “Yeah, me too. Yeah, they’re so...I don’t know. If they make lots of money then I look up to them” (FNG#4d).

Following someone else’s way of living whether it be a mother, father, older sibling, or even grandparents were shared as role model experiences. For example, one youth describes the sibling he is modeling his behaviour after, “I think its, well for me, it’s my older brother, I think its more an older brother or something. I never met my dad” (YDC#12). Some youth blame the role models in their lives for what they are currently going through. “Yeah sometimes, they blame their parents, or their grandparents for what they’re doing. Like my sister, she does, she drinks. I don’t know if she still does, I haven’t seen her in a while. But she drank and did drugs and she blamed in on the way she was raised” (FNII#5).

Other youth found positive role models in foster care: “I’ve been in a lot of different towns, been in different foster homes, have been taken into different families, and they’re usually good foster homes. They would expose me to their real families and stuff, like they would take me to their thanksgiving dinners and stuff and I would be like part of their family” (YDC#12).

Themes such as learning from the past came up many times in the interviews. The youth shared that it was through their difficult experiences that they had often learned that their parents
or guardians actually had been trying to protect them, that they loved them and that the discipline they had resented when younger was not punishment. Some youth yearned for the love that they experienced in the past before they were apprehended, one youth expresses remorse of not understanding his parent’s tough love, “Yeah, I’m starting to realize that a lot of punishment in the past has been out of love. And once you lose it and once you do get the freedom you want you start to fall downhill and you realize why and you sort of want it back. You sort of realize this tough love was for your safety . . . and since I’ve been in here [youth detention], I just started realizing that. My mom just wanted me to be safe. And I used to just forget about it, but then I realize now that she just wanted me to be safe and be at home. Make sure I was alive or something” (YDC#14).

Some youth may have someone they can count on even though they have experienced being in trouble with the law, “He’s just there when I need him. Whenever I need help he’s there...like if I’m in jail he’ll be there, to the courts, to let me out. He tries to track me down if I’m ever at my friend’s house or out late. He’ll give me shit if I’ve come home late. Breach my curfew, and he tells me I’ll go back to jail if I keep doing it. So he gives me the heads up, just to get it in my head. I don’t listen, but...”(YDC#12). Some youth verbalized how tough love is ineffective method of preventing risky behaviours: “No, because if I think they loved me they wouldn’t want me out. They would try and help me themselves. Try and help you if you got problems like that. Help you themselves” (YDC#13). Similarly, the youth in the following quote describes a possible reaction to a tough love approach:

Like kicking them out? Don’t! I think that’ll make them even madder... That would make me want to go do drugs! Yeah, like this one girl that I know, she’s a volunteer for Young Bears and we were at a meeting, she was sharing that, uhm, yeah, that her parents tried to kick her out. She left anyways. So I don’t really think that uh... Yeah, I don’t think it works. It actually makes them feel more bad cause they go do drugs and then they have nowhere to go so, they only have the drugs to make them happy and then they feel
like that’s what they only got. And I guess they kind of lose . . . like they don’t even know who they are anymore. (FNG#1a)

The youth described how there were no public role models for them to look up to. For example, one youth expressed his thoughts on not seeing professional First Nation role models, “I’ve never seen any professional skateboarders” (YDC#15). The youth also mentioned that there are no First Nations people on television, no famous athletes or actors or politicians, the kind of personalities they might look up to.

From the Youths’ perspective, there is a need for a foundation for them to stand on to be supported. Many of the parents or guardians of the youth have experienced Residential Schools and have become survivors in their own right. It was evident that many of the youth experienced not having parental/guardian support for the most part and for those who did. Their experiences of being parented were very minimal. With a significant lack of role models in the home and in the public domain, the youth are left looking to their peers for role models, people who are struggling with the same problems they are, and who are often modeling the risk-taking behaviours healthy role models might have the potential to lead them away from.

*The Paradox of Being First Nation*

This study reveals the perception amongst high-risk First Nation youth that First Nation culture has been eclipsed by alcohol and drugs, which in turn have become synonymous with being First Nation. As one youth said, “I think [for] some kids, their culture is drugs” (FG#1a). This means that the First Nation youth, while being considered First Nation by blood, are not living the culture of being First Nation. Many of the youth expressed not living as First Nation’s people, and one female explains how this affects youth, “There’s not that much people to teach them anymore cause, some people have forgotten their culture, and I guess, I don’t know, they
just don’t learn as much as they could” (FNII#11). While some youth may be interested in First Nations culture, they do not see it as relevant to their life stage. This viewpoint is likely strengthened because they see others party a lot and then change when they get older. As one youth says, “Maybe I’ll get into culture when I’m older. Right now I don’t really, I think I know enough, but when I’m older I think I might want to get to know a little bit more . . . I think I would be more interested” (FG#1a).

The lack of established culture around them causes a dilemma when it comes to youth deciding what culture they come from. For example, I posited that if we take a table, and on one side we put regalia, and on the other side we put risk-taking such as alcohol and drugs, and asked which they would choose. Most of the youth chose the alcohol and drugs. One said succinctly, “Probably grab the liquor and run,” (YDC#15) while another youth stated, “Yeah,” he would grab the liquor, but at the same time, he stated he would grab the regalia if he was “in the right state of mind” (YDC#14). It seems clear that there is little foundation supporting him in choosing the regalia.

Experiencing First Nation culture would mean that you lived in the environment of cultural activities as they occurred daily. However, truly meaningful cultural activities are evolved over long periods of time, and over the past seven generations, First Nations people lost their cultural structures through effectively being denied the right to exist as First Nation people. Due to the stifling of First Nation culture through prohibitive legislation, First Nation people are still recovering from having been forced to ask permission to practice their culture. Not only were they denied their own culture, they were also excluded from the new dominant culture; historically, First Nation people in Canada were not allowed to participate in voting because they were considered non-Canadian. The previous statement is made from personal experience and
from hearing this from family and community members of the inability to vote because of the laws of Canada. One youth described the importance of needing this permission to be First Nation by claiming, “Whenever we gather, we have to have some sort of license or something like that. Or it has to be in a special place, like the Native Centre. Like I guess back then, they didn’t need permission from anybody” (FNII#11). Many of the youth described learning some culture from school or other people, therefore, not living First Nation. As one youth mentions in her introduction of herself and where she learned some of First Nation culture in a non-First Nation environment: “I went with that white program and we did a bunch of cultural stuff . . . sweats, uh, the cold baths, the warming ones, the different kinds of medicines and . . . Yeah, different songs I learned” (FNII#10). I asked what learning about First Nation cultural activities meant to her and she responded with, “Uh, it made me feel different, learning different stuff. Nothing like I ever did before . . . Uh, it feels good actually” (FNII#10). I also asked her if she would continue on with these cultural activities in her present life and she responded with, “When I have kids . . . cause my aunty was the one who always brought it up a bit . . . she’s passed on” (FNII#10). One female who comes from a background of three different First Nation blood grew up with her half-Inuit, half-Cree single mom who did not practice First Nations culture. She shares the following about growing up with no culture: “I lived with my mother, but she didn’t know much about our culture because she’s deaf. And not our whole family knows how to do sign language. So she didn’t get to learn much” (FNII#11). She then continues with regards to her own barriers of learning her culture, “I started learning that [her own First Nation language] for about a year, but then I moved away and the other schools won’t let me learn that. I had to learn French. And then I came here and they taught me to make dream catchers, taught me to sing songs, that kind of stuff” (FNII#11).
One youth who was interviewed at a pow wow and is a dancer expresses her thoughts on what keeps her strong, "So, for me it’s just to know your religion, and just to know who you are. . . and even it’s being West Coast or it’s being Prairie, . . . cause they all have their own traditions of doing their own religion. I think it’s just once you get to know who you are and what you do in your culture, its kind of . . . that’s where it empowers you over drugs and alcohol cause . . . it brings your spirit up" (FNII#9).

One participant shares her story of being picked on for being 'native' and how she was the only native student in her school and called names for being native such as ‘drunk,’ asserts, “Uhm, well she [older sister] told me that all this stuff they said weren’t true. That all natives weren’t drunks. They don’t have to be, its not all they’re gonna be. And that being Native doesn’t mean that I’m of a lower class or anything” (FNII#11). She goes on to state “it made me feel good that I learned all the stuff here, and now I’m proud to be Native” (FNII#11).

It was clear from my findings that there is a desperate need for role models among First Nations youth if they are to change their risky behaviours. They are disillusioned with their Elders, parents and relatives, all of whom they too often witness falling prey to these same behaviours. They lack a cultural framework to demonstrate ways of living and meaning that they could rely on to provide good examples and a feeling of belonging that would be something to hang onto and provide guidelines. They have no heroes in popular culture, in which the ubiquitous images of fame and success leave First Nations people almost completely unrepresented. Their recent historical background is a history of oppression, persecution and discrimination. Without a new set of values and beliefs, the youth have only themselves to rely on, a situation that is very occasionally successful, but mostly leaves them in a vicious cycle of risk-taking.
Access to Health Care

My findings on health care include an assessment of the youth’s awareness of HCV as a disease, their knowledge of those with HCV and how they care for themselves, how to manage risk, and prevention recommendations for youth healthcare.

Awareness of Hepatitis C

HCV awareness in the First Nation youth was evident, but there were gaps in accurate knowledge. One youth thought that HCV could be contracted by, “probably uh, for youth. . . . a lot of youth smoke weed, so like the cuts on their lips or something, probably passing it through a joint or uh like the thing of passing it through needles or if you got a cut in your mouth and if you share a drink” (FNII#2). Many of the youth confused HIV and HCV as being the same disease with the same risk factors. One youth emphasizes how a person might contract HCV by, “unprotected sex, sharing needles, like drug needles [and] tattoo needles” (FYII#4).

Knowledge of someone with HCV and how they care for themselves

Three of the participants have a parent with HCV. One of them acknowledges her mother’s self care of her HCV:

When she found out, she didn’t change it [care for self] right away. But uh, a tragic thing happened so she, that’s when she did change her life. But when she, she did have hepatitis for a long time, so she wasn’t I guess she in a way she cared, but she didn’t care. So. . . .now that cause, uhm, she was still on the road of her . . . the bad road, the black road. And she thinks that, if she still did what she was doing then she would have died in the next year or something cause it was getting pretty severe. But then she went sober and so now her current health is going upwards. (FNII#9)

It is important to note that these youth are observing family members with Hepatitis C, and therefore becoming aware of the consequences of risky behaviour; but also continue to witness their parents struggle, just as they saw them taking alcohol and drugs when they were smaller.
Managing risk

Surviving being at risk takes on many facets. Youth learn from those around them and their problems; they learn from their own mistakes; they rely on their own strength and intelligence for survival. Many of the youth had a parent, guardian, relative or friend with HCV. They assert they do not want to end up like them. The youth who know someone with HCV state that the people with HCV take care of themselves and stop taking risks so much, “I have learned a lot about Hepatitis C, drugs, and drinking. Cause my mom has Hepatitis C, so, watching her, you kind of learn about it just by watching” (FN11#9).

One youth talked about being as the necessity for being smart in order to survive:

Or if like you’re a drug dealer, and your responsibility is to make sure that you don’t get caught, and you don’t just . . . you kind of know how to sell it and you have to know how to take care of your money and not just go spend it right then and there and then you have nothing . . . You have to know, I guess you kind of have to be smart, right? . . . You have to make more money than you pay for [drugs]. Yeah you have to make a profit all the time, right? . . . You have to be smart actually” (FNG#1a).

One of the youth who lives apart from any of her parents/guardians shares how youth need to be strong: “I guess some yeah, are strong. They’ve gone through enough, or if they’ve had both parents when they were younger but they, a lot of youth learn their own behaviors these days, like, speaking for myself, uhm, I’ve, I did go, I was lost of a little bit. But uh, I didn’t have any of my parents. I felt like I didn’t have anybody. But that is also being where you are teaching yourself your own things, where being strong causes you to learn to look after yourself” (FNII#9).

Prevention Recommendations for First Nation Youth

Like the Elders, the youth felt it was important to start educating children on HCV, even as young as children in Kindergarten, “Yeah, but if you keep talking about it through
kindergarten, and then you talk about it through grade one, if you talk about it in grade two, three
four, five, and you just keep talking about it, then I think people will realize that it's not good!”
(FG1#1a). This participant compares this to when one learns to walk and how early experiences
stay with you, “You know when you’re little, right and you learn how to walk and how you’ll
always have that with you . . . if we teach the children when they’re younger, they’ll always have
that in their heads” (FG#1a). This comment stems from the recognition that many youth do not
have continuous role models, for instance, parents not being there consistently. The youth feel
that if something is important enough, the information about it should be provided repetitively so
that the information is easy to remember and stays with them. The youth even go on to say that
Elders need education as well because they do not know what their culture is exposed to and
need to realize this.

The Elders felt it was important to ask the youth if the youth would feel comfortable
taking on educating family members on HCV; the youth’s response was positive. They said they
would feel comfortable teaching family members about HCV. One youth suggests, “Yeah, I’m
going to talk to my sister about it, my little sister” (FG#1a). The youth express comfort in
sharing information on HCV to family members, “I would read them that booklet you just gave
me” (FG#1a).

One female and one male youth in a focus group interview who were not afraid of
sharing information expressed practical ways youth can learn both to drink lightly and prevent
STDs: “Some people should just learn how to social drink, like sip on it, sip on it you know?” . .
. Yeah, I always carry a condom in the back pocket when I go out drinking” (FNG#1a). Deep
down, youth also seem to want to please their parents or be responsible, “It’s just showing your
parents you can get a job and staying away from old friends that get you in trouble, where you . .
friends you hang around with get you in trouble, and stuff like that" (YDC#15). Another youth talks about friends’ betrayal and how it is important to get away from those who betray you and to gravitate towards those you can trust. “Me personally, I’ve always loved pow wow dancing and knowing my religion and going, cause people at the pow wow are really, they show you that kind of love and friendship and they’re not going to betray you like that” (FNII#9). One male participant affirms that education on HCV can occur at gatherings, “you can do like, big gatherings I guess...like the Salmon Run... In, uhm, White Rock, you can talk about it there, or when there’s a pow wow in the North or something” (YDC#12).

A common theme among the youth was to, “Learn from your mistakes. And if you never learn from your mistakes, learn from mine” (YDC#14). Others recognize that mistakes can be costly, “You just get a vision of what you could end up like if you do that stuff and it scares them away from it. That’s why I’m not, I don’t do that kind of stuff, because I see all the people down on the... and it’s mostly First Nation people too down on Hastings and everything” (YDC#12).

Some youth described guardians and parents expressing love or discipline as someone trying to help you:

It depends on how you look at stuff. Say if there’s a treatment program, say if you were sentenced from court to go to this treatment, you’d sort of look at it sort of as a sentence, because the judge wants you to do something or to keep out of trouble. People should like, if they would look at it as a more positive, I mean, they would realize that it’s not sort of, it’s not a sentencing, it’s not your being sentenced to do it, you’re not being in trouble, it’s just you may be in trouble, but they’re trying to help you get out of trouble and stay out of trouble for the future, not for the justice system, for yourself. (YDC#14)

Another youth remarked that there are opportunities for help, “Look at all the opportunities available to help you. Not as a sort of task that you have to do, but as a helping hand and people who do care and do want the better for you, rather than having responsibility taken” (YDS#14). One alternative to risk-taking that involves alcohol or drugs the youth mentioned is risky sports,
to keep themselves busy, or just cause they like it, its fun!” (YDC#14). One youth asserts, “Just don’t do the hard drugs, and make sure you check tattoo tools and dirty needles and stuff,” (YDC#12).

However, another youth makes a comment recognizing the difficulties associated with resisting peer pressure and sharing needles:

Maybe not hanging out with needle users ... I know I wouldn’t want to be hanging out with needle users. I was in a house one time where I was smoking drugs and then uh, the guy came in and he dropped, he put his needle on the table and was like “Anyone know how to do it?” he was so messed up and stuff. And I was sitting at the table and I was just like, ohhh and I almost puked right there, because I just finished smoking drugs... and then what’s her name, this girl grabbed the needle and she was like ”There’s kids here” and she smacked him and he got up and he pulled out a big bag of crack, cause he was a drug dealer, and then they walked in the washroom and then he’s doing it and he sat there for hours and hours. And then he came out and he was just sweating and jerking off and I was like ohhhh, ran to the toilet, puked and left the house. I didn’t like hanging out there. (FG#4d).

Self Care and Thoughts of a Future

Throughout the study, the youth mention that they are not ready at the moment to pick up the First Nation culture, or to think of a future. When asked about the (Red or Black) paths they would take, some of the youth alluded to the fact they learned their lesson and changed the paths they were on by stating, for instance, “Yeah, I was on the Black Road before I came here [youth Detention Centre], but, uhm, I’ve worked my way back to the Red Road now” (YDC#3).

Responses on self-responsibility span from harm reduction to thinking of a near future. For example, the youth express wanting successful lives outside of their risky-lives, said, “I don’t know, I’m going to get out of here and get a job,” (YDC#1) and “Yeah, I don’t think needles or anything like that are going to be a problem, just because I know the dangers and have seen what could happen to other people. I pretty much want a successful life. Just pretty much working for a living and progress” (YDC#2). Storytelling is a way First Nation learn, one of the female
participants talked about her vision for her future, “Myself, I want to express myself through talks. Like, I want to start talks when I’m able, when I’m finished school. I want to see how I can get into talking to youth elementary schools and stuff” (FNI#7).

Learning lessons from the past helps youth to make choices. For example, when they realized that their parents/ guardians were strict in not allowing the youth out for whatever reason, one youth explains, “You can’t really give that message, it’s just sort of a life learning experience. Once you lose that, sort of whole person looking out for you and grounding you, making sure, like you ask to go to the movies and they say no for whatever reason, until you do get that freedom to realize what they were trying to do in the past . . . that’s the only way I opened my eyes and realized to take the opportunities that are given to me—to help me” (YDC#2).

The youth talk about the future in the context of witnessing others change their paths to the Red Road path, which includes a fresh interest in First Nation culture, for instance, “Some people it’s different. The culture might turn them over . . . I know someone that is like a Medicine Man now, and he used to do lots of drugs and stuff but then he said that he learned how to keep himself busy and then he turned into a Medicine Man” (FG#1a). When asked about the path the youth would like to take, one female participant answers, “They have a lot of good choices. They have like a whole bunch of choices, like they can take one road or the other. One road will lead to something good, but it’s harder. One road you don’t know what it’ll lead up to but it’s easy. Most people try and take the easy path, but that’ll usually just lead to something bad, like ditching school, doing drugs, not finding a job” (FYII#4). This quote illustrates the fact that the youth are more concerned with having fun now, and tend to treat thinking about health and responsibility as something one does later on in life.
Conclusions

The study shows the roots of youth’s risk-taking behaviours that put them at risk of contracting HCV. The Elders correctly assessed some of these roots, and the questions they encouraged me to ask the youth clarified others, such as the availability of drugs amongst the youth, and the need for role models. I gained valuable insight into ways to help the youth live healthier lives, as well as a painful awareness that they are in a very difficult time facing enormous challenges.

Issues identified by the Elders for putting youth particularly at risk for behaviours that increase the likelihood of contracting HCV stem principally from the many external influences currently available to them, in particular: the accessibility of drugs, new drug paraphernalia and rituals; the influence of others, for example, drug pushers; and technology, such as television and video games.

Key themes that emerged from the analysis include: surviving risky lives; in search of positive role models; being a First Nation youth means taking risk: being a member of a culture whose traditions have been eclipsed by violence, drugs and alcohol; accessing health care; and the awareness of HCV. Five sub-themes emerged from the youth’s experience of surviving risky lives, including growing up at risk and the subsequent normalization of risk; progression of risk taking; accessing alcohol and drugs; reasons for risk taking and moving towards risk prevention.

From these themes, I have established recommendations for both First Nations people and the medical establishment regarding the needs of First Nation youth and ways that might be effective in offering them help in countering diseases like HCV, including education in First
Nations culture and developing a more holistic approach. I will develop these recommendations in Chapter Five.

Perhaps most importantly, it became clear that the youth need love and stability, and they need to regain pride in who they are. Youth who had experienced the risk-taking lifestyle of substance abuse stated they would choose the alcohol and drugs if they had experienced it already. On the other hand, youth who had not yet experienced the life style stated they might choose their culture, no matter how compromised it has been, that they would grab the regalia or walk the Red Road as opposed to the Black Road.

In particular, the youth are looking for love/ nurturing and stability. They are also looking for a sense of connectedness and an identity that will give them a foundation that seems more attractive than the excitement of living dangerously, a framework that would help them envision a healthy and empowered future. Parents are still experiencing the intergenerational abuse of colonization; as a result, the Residential School syndrome cycle continues. There is no foundation for which the First Nation youth to take hold of, making the risk factors easy for youth to cling to instead. Parental/ guardian presence in supporting youth is largely absent, leaving youth at risk free to do what they want.

Despite the problems they face, the youth are resourceful and often admirably self-reliant. It is important to outline paths to wellness that emphasize being strong and courageous, in order that they may feel proud of themselves and start to create role models who they can look up to. The Elders’ hope that prevention programs would focus on wellness rather than on the diseases seem to tally with this conclusion. This would also address the accountability for one’s actions that the Elders identified as lacking in the youth, as well as placing an emphasis on health education and issues like safe sex.
As the traditional leaders of the First Nations culture, there is an urgent need for healthy Elders as leaders and visionaries. An essential element of my wellness recommendations will be the question of how to bring in Elders in ways that are not threatening to the youth, but rather on an invitational basis.
CHAPTER FIVE: DISCUSSION OF PRACTICE RECOMMENDATIONS

Chapter Four detailed the findings of my community-based research and ethnographic study focused on reasons why First Nations youth are at high risk for contracting HCV. In this chapter, these findings are discussed with reference to other researchers' studies, followed by details of the implications including practice recommendations for programming and education that address the identified issues.

In this study, ethnography research methodology, guided by a community-based research philosophy, was used to examine why First Nation youth are at a high risk for HCV within the 13 – 17 year old age group, and to explore what recommendations Elders and youth have to offer on the prevention of HCV. I chose this method because it focuses on the needs of the people being studied; a prerequisite of this style of research, established by the University of Victoria Faculty of Human and Social Development (2003) is that “the findings of the research will be presented in a format that is readily understandable and accessible to all stakeholders, and particularly to those who provide the basis for the research findings. Where appropriate, the research findings will be presented in oral, written and visual forms in both Indigenous and non-Indigenous publications and forums” (p. 8).

The Braid Theory that I developed in 1999 forms the guiding rationale for the discussion and conclusion in this study. The techniques of ethnography, such as interviewing subjects in their own surroundings, and community-based research, in which interviews were conducted to Elders’ specifications, with prayer at the beginning and the sharing of food, conform to the principles of the Braid Theory and its emphasis on a holistic approach. The issues being studied were considered in the light of the Braid Theory and include:
Mind: Dealing with the psychological aspect of the situation means dealing with the lack of parenting skills among First Nations adults, the high level of addictive behaviour, the Residential Schools experience, and changing First Nations’ self-image as drunken Indians. On the positive side it means increasing people’s self-esteem and pride in their culture.

Body: Addressing the physical problems of risk of HCV means practicing risk reduction around ways of contracting HCV, stopping the cycle of violence many First Nations youth experience and then do to others, and increasing the level and accepted-ness of physical affection among First Nation families.

Spirit: The spiritual strand requires an emphasis on reintroducing First Nations culture, encouraging attendance at ceremonies, being given a Spirit name, becoming an Elder or role model, believing in a future, attending gatherings, and finding meaning in life.

An approach that considers all three aspects of a situation creates a solution that is difficult to break, like three strands woven together, whereas an individual strand is very easy to break. Interweaving these three elements has the potential to create a strong plan based on empowering communities, families and people.

The study demonstrates that there is a great divide in how Elders and youth view youth’s role for the future. Traditionally, First Nation people think of the Seven Generations ahead of the one they exist in. However, today’s First Nation youth are putting aside their future until a later time in their lives when they are ready to “be in the culture of First Nation.” Paradoxically, they define their actual culture as one that features being at risk.

Surviving risky lives

One of the Elders’ main concerns was that the children have no supervision. However, it was clear from the discussions with the youth that those who should be supervising them are
unable to. Most of the youth therefore experience parenting as being suffused with alcohol, drugs and violence, as well as sexual abuse; they are born into an atmosphere of risk that becomes normal to them, leading to a high frequency of addictive and self-destructive behaviour. The reasons for this are rooted in the parents’ experience in Residential Schools, which has resulted in their inability to provide stable, loving homes. The last Residential School closed in 1984, meaning that many people who grew up in that environment are still becoming parents today. This upbringing causes a vicious cycle, in which the parents act out their problems through addictive and abusive behaviour, and this becomes normality for the youth, who then seek out and replicate similar behaviours, creating a culture of risk. There is also an absence of physical affection due to the parents’ lack of experience of parental love, combined with fear of hyper-vigilant child protection laws that often misconstrue physical affection as sexual abuse.

*In search of positive role models*

The Elders and the youth both expressed the concern that the youth have no role models. In the absence of adequate parenting, public figures could have a formative and helpful effect on First Nations youth struggling to establish an identity. However, youth report seeing no images of successful or rich First Nations people, for instance, not seeing First Nations athletes or characters on television or in films. They have no one to admire and no footsteps to follow.

The Medicine Wheel (1985) is a First Nations philosophy that considers the four stages of life: child, adolescent, adult and elder. The relationship that occurs between an Elder and a youth is depicted as one of teaching and learning. The Elder’s job is to teach the child and the child’s responsibility is to learn from the Elder. Therefore, in traditional First Nations culture, the youth looked up to the Elders. However, the youth I interviewed report being disillusioned with their Elders because they have seen some of them displaying addictive behaviour, and also
because the youth see no place for traditional First Nations culture in the present world, regarding it as something to do when they are older. Their parents, who would normally be key role models, are as mentioned largely unable to fulfil this role.

Brentro, Brokenleg and Van Bockern (1990), states that they “saw ‘mistreated, abandoned, rejected, wounded children’ as growing in environments where the seeds of discouragement had been planted. As these children develop, they encounter increasing difficulties in social and emotional adjustment. Their lives become ‘flowers of evil’ marked by mental illness, delinquency, depression and defeat” (p.8). The youth’s self-esteem is also damaged by the image of being First Nation meaning being a ‘dumb, drunken Indian,’ this being the prevalent social message about being First Nations, and there being no popular images of First Nation success to replace it with. The youth drink and take drugs both to act out this label, as some of them come to believe that it is true, and to try and forget the label.

*Being a First Nation youth means taking risk*

The Elders are concerned that the youth have no cultural experience; the youth do not even talk about First Nations culture other than in the context of drop-in teaching they receive in school. The youth culture and what it considers ‘cool’ has instead become one of taking risk.

In the absence of stable parenting and guidance in the form of role models, the youth growing up without the structure and meaning of cultural belonging adopt taking drugs and drinking as their way of sharing an identity. Messages from television and other media that it is ‘cool’ to have money lead to the youth selling drugs for income and seeing a dangerous lifestyle as glamorous. As well, in their search for a feeling of belonging, it is very attractive for the youth to be in a group, and therefore they often take drugs or drink due to the feeling of connectedness this brings, as well as peer pressure.
According to the Elders, the youth are the future leaders. In First Nations imagery, the Eagle flies high overhead and sees the big picture, and is therefore able to offer guidance; the Elders are thinking from the Eagle’s point of view in their vision for the youth’s future as the future of First Nations culture. However, the findings on this study showed a major disjuncture with the youth’s point of view that they are putting the future aside, and are only concerned with now. They think like the Mouse, only dealing with what is immediately in front of them, as described in *The Sacred Tree* (1985): “Our little mouse sister does what she does with all of her tiny being” (p. 45). Because it fills their vision and affects their whole lives, eliminating the paradox of having only a culture of risk is one of the most important ways to help the youth.

**Health care**

The interaction between medical staff and First Nations is complicated by First Nations’ history and experiences with Western authorities. The Elders are afraid to visit doctors due to the abuse they experienced as children in Residential Schools. Ironically, the youth are not afraid to visit doctors, as they view getting necessary medicine as a practical measure; however, they do not go to doctors with their real life problems. The unstable situation most of the youth experience leads to a general absence of and ignorance among them about health care. This problem is added to by the medical establishment, which tends not to address the youth’s overarching issues. The Elders are concerned that doctors do not assess health holistically, thus missing important information about a patient’s background and present situation.

Also, there is frequently a communications challenge when First Nations people visit doctors, as they don’t want to ask questions because they don’t want to seem stupid. The imbalance of power and knowledge between the First Nations person who feels discriminated against and at a disadvantage when faced with a doctor’s knowledge suggests the need for
education of the medical establishment in First Nations history, culture and specific issues to enable them to compensate (Smylie, Lessard, Bailey, Couchie, Driedger, Eason, Goldsmith, Grey, O’Hearn, and Seechram, 2000).

*Awareness of HCV*

The youth do not have authority figures who they look to or who give them advice, they have no cultural framework to repetitively convey messages about risk-taking behaviours, and they are most influenced by peer pressure. They do not interact with the medical establishment other than to get medicine when they are sick. Due to this lifestyle, most of them receive no education in the specific risks that lead to HCV. Many of them confuse it with HIV, and show no awareness or concern for their likelihood of contracting HCV. The drug-taking behaviours that the majority of them participate in are the main causes of infection, with a lower percentage resulting from unsafe sex. However, there are no programs addressing HCV, and there is a similar paucity of literature on this subject.

*Implications of the Findings*

The findings of this study regarding decreasing youth’s participation in risky behaviours that lead to HCV have implications for health care and the medical establishment and the programs it offers as well as its methodology when dealing with First Nations people. There are implications for education in schools, and for the introduction of youth to First Nations culture, which requires active cultural reintroduction on the part of the First Nations people. The practice recommendations drawn from these implications follow, divided into the three principal areas under consideration.
Practice recommendations for Health Care

Programs that provide healing and support services for those who went through Residential Schools need to be continued. The existing Healing Fund that deals with the Residential School issue is only just beginning the healing process for those generations that attended these facilities and for their children and grandchildren. A background paper on HIV/AIDS and First Nations people prepared for the Special Working Group on First Nations issues, Ministerial Council on HIV/AIDS (2001) describes the core initiative:

The “Gathering Strength” initiative was the federal government’s commitment of $350 million to support community-based healing initiatives for First Nations people, on and off reserve, who have been affected by the legacy of physical and sexual abuse that occurred in residential schools. The First Nations Healing Foundation was formed in 1998 with the responsibility of allocating these funds. The Foundation’s mission is to encourage and support First Nations people in building and reinforcing sustainable healing processes that address this legacy. (p.24)

This project and others like it must continue throughout the country so that recognition and understanding of the damage done increases and the cycle of abuse and addiction stops.

In order to be more effective in their communications with First Nations people, the medical establishment would benefit from making an effort to learn their culture. It would be useful, in terms of getting health care information through to the youth, to get input from them on how workshops, curricula, health programs and publicity materials such as brochures should look. University curricula could be developed that encourage doctors to assess patients holistically, using the Braid Theory, so that they can address the real problems rather than applying Band-Aid solutions over and over again. Physicians and nurses must understand that they will be more effective if they make the time to ask probing questions and be patient, while making visits non-threatening and friendly. They should also be aware of issues First Nations are
most at risk for, and have on hand printed and general information on local and accessible resources for addiction issues, housing, financial support and health options.

Counselling and workshops, incorporating traditional beliefs and values on learning not to be violent or abusive with others would be beneficial; First Nation people also need more HCV workshops aimed at youth that incorporate traditional practices, e.g., sharing food, using culturally relevant material, and listening to someone with HCV storytelling. Health messages would be more likely to reach youth if they were attached to music, e.g., rap; art, First Nations design; and presented at gatherings where dancing and drumming take place, via speakers referring to issues where First Nation cultural protocol is followed. One youth, alluding to the need for self-protection, mentions, “You don’t think people want to get sick on purpose?” (YDC#12). This would be an effective message if presented on posters or brochures or as an advertisement on television.

Every First Nation community has a leader in health promotion. In order to help First Nation people deal effectively with the medical establishment, it might help to encourage them to go to the community health leader and get directions on what questions to ask doctors so that they feel at less of a disadvantage. This might have an added benefit, as more First Nation role models would emerge if leaders actively seek to identify and promote those who are community-involved. There is a significant increase in the number of well-educated, activist First Nations young adults who might act as role models, such as Nadine Caron, MD, and Ginger Gosnell, national youth role model. The existing and new upcoming role models need to be more visible to First Nations youth.
Practice recommendations for education

The problem of youth living in a culture of risk is so deeply rooted that it needs to be addressed at the level of education for both youth and adults. Canadian Society would benefit from learning about First Nations culture as with the First Nations youth learning about the non-Aboriginal cultures. This can be in the way of an immersion type of setting, where each are immersed each others culture, learning first hand about each other. There is a case for advocating for more education in schools on the truth about First Nations history and culture, as these form the roots of the problem. The education system needs to have text books or curriculum that tells the truth of the history of First Nations people of Canada so that there is a better understanding of why First Nations people find it difficult to navigate the education, health, and judicial systems. If society do not learn about the real issues of First Nations people, the cycle of abuse continues and is perpetuated by the media that portray First Nations people as ‘dumb drunken Indians.”

Parenting skills classes in First Nations communities would be useful, as well as initiatives that could be introduced in schools to encourage youth to share their culture. A document prepared by The ANAC named, “Healthy Children Healthy Nations, (No year), encourage “parenting courses incorporating the community’s traditional parenting techniques be developed and given in every community,” (p. 49) Once youth present themselves and the details of their culture to other youth there is often a renewed perception of First Nations culture as ‘cool.’ Teenager John Miller at a Richmond school, one of 5 First Nations students, shared his culture with the whole school and won a Leadership award. This kind of acceptance enables youth to be proud of their culture and to choose it over the drugs and alcohol, recalling the concept of the table with the regalia on one side and the drugs and alcohol on the other mentioned in Chapter Four.
Programs such as these also fulfil the need for role models, as students begin to feel like leaders. Programs qualifying participants to become student mentors in which they could invite guest speaker Elders and role models from other communities to come in and talk about how they attained their leadership roles would give youth a sense of belonging, and replace the stigma of being a ‘dumb, drunken Indian’ with responsibility and recognition.

Two role model programs exist, the National Role Model Association and the Chief Health Committee Careers, however, there is not enough evidence to assess whether these programs effectively engage youth or teach them how to be role models. The Elders’ opinion is that discipline is a central component needed to become a role model, something that could be taught in coming-of-age ceremonies. Coming of Age ceremonies teaches how one is responsible for one self’s actions and to accept the consequences, whether they be good or bad. The ceremony involves whole families and communities, providing the person experiencing the ceremony as belonging to a community. One such project developed by Chee Mamuk (2002) in collaboration with local lower mainland First Nation cultural workers was a success. The project called, Chako, To Become, is in its third copying of the video and guidebook. The youth need to receive the message that staying in school, completing your studies and, most importantly, finding a passion, such as being an accomplished teacher, nurse, doctor, basketball player or even real estate agent, can turn bad experiences into a life that works for them and enables them to stop the cycle of bad parenting.

Supervision and role modelling could also take place in after school programs, such as those run by the Urban Native Youth Association, where Elders could put in an appearance regularly. These programs have the potential to provide an introduction and a welcoming to learning about First Nations culture, and to act as an ongoing influence on bridging the gap
between cultures, opening the doors with an emphasis on getting rid of the ‘us and them’ mentality.

**Practice recommendations for cultural rehabilitation**

The fact that the youth do not talk about Spirit indicates a lack of spirituality, beliefs and values that puts them at risk. It is very important for all First Nation people to change their goals, to recognise that they do not have to accept the label of ‘dumb drunken Indians.’ The Elders felt that encouraging the youth to learn about the philosophy of being First Nation would deter them from taking unhealthy risks. Many learning opportunities are available, through storytelling, ceremonies, by repetitively doing and seeing. According to Steven Acheson (1995), “the faith of the patient has much to do with his recovery . . . the ceremonies and prayers are well calculated to inspire this feeling, and the effect thus produced upon the mind of the sick man undoubtedly reacts favourably up in his physical organization” (p. 20).

Like the progression into risky behaviour, the return to cultural practices is also a gradual process that builds. As one youth said:

I think it’s a progression, I honestly think of progression when . . . a person starts going through sweats and when a person starts having pipe ceremonies . . . They just finished coming from a sweat, but on my mind, my mind is still not all that strong. So I could be tempted to say, “OK, hey there, offer me some coke. And I’ll do it. It doesn’t mean it’s going to be just like that (snap of fingers) once you go to a sweat. No, it’s a progression.

Youth must be encouraged to attend gatherings such as powwows and the longhouse to experience the protocol and what the culture has to offer, such as competitions in dancing and drumming, traditional food, Elders for consultation, and the opportunity to develop extended family relationships, which would create a greater support network for them in the absence of adequate parental support. An added benefit is that no drugs and alcohol permitted at ceremonies, and youth can treat them as a place to get away from troubled friends. In the past
First Nations people worked together to overcome problems and the welcome to attend ceremonies within the community lets people know that they are always welcome, encouraging them to let go of feeling shame and reorienting them to seeking help.

In order to reintroduce First Nations culture, it is necessary to reintroduce the traditions and philosophy of being First Nations throughout First Nation communities. These include respect, courage, value of generosity and hospitality; First Nations people were always proud to treat strangers as guests. A quote from a Chief in 1906, cited in the T’IT’Q’ET Comprehensive Community Plan (2000), describes how the Chief should act kind, generous with all people and to be welcoming with no judgements on anyone (2000).

Physical messages would be helpful for getting people to attend ceremonies, such as posters on positive aspects of being First Nations, times and places of ceremonies, the fact that everyone is welcome, that counsellors or Elders are available, as well as the invitation to experience culture and discover healthy choices.

The current generation of Elders is the last that grew up with the remains of First Nations culture, and the Elders perceive a need to guard against ‘weekend’ medicine people who are not truly committed to the tenets of the culture. There is therefore an urgent need to develop an Elders’ council where Elders could mentor people in becoming Elders. As the tradition is oral and sacred, the teachings must be passed on in person. This is one way to bring together the youth and their Elders and help create a sense of belonging, cultural pride and identity, and to establish clearer role models from within the community. A forum for this is already established, as First Nations conferences often provide youth and Elders forums with dedicated rooms so they can meet together. Similarly, Elders could mentor parents and youth in traditions in the home, e.g. coming of age ceremonies where a person receives their Spirit name and learns the
responsibility of becoming an adult from a child. This would reintroduce the culture and the support it offers into the damaged atmosphere of First Nation’s homes.

However, there is also a need to talk to the Elders about how to make traditions relevant to the youth by creating a balance between Western and First Nations culture that recognizes the youth’s everyday reality, including modern roles of men and women, the social emphasis on success and money, the prevalence of television and popular music as influences, and the need for the youth to conform with their peer groups in the larger community.

An example of the contrast between the ways western and traditional First Nation medicine regard disease is described Evelyn Voyageur, a First Nation nurse with the Kwakwakak’wakw people of Vancouver Island:

Once, health was said to be the absence of disease. However, the First Nations always believed it was what Gail Siler-Wells (1988) said: “Health is being fully alive, physically, mentally, spiritually, emotionally and connected in a fulfilling way.” This is what children were taught and how they were treated even before they were born. (p.5).

The Elders’ attitude is that we should talk about wellness, not focus on the diseases. New programs should emphasize the strength and survival skills of First Nations people despite their problems, establishing more messages about the strength required for reaching out and seeking a different way of living. This would be effective with both parents and youth, as it would be courageous of them to choose a different path, the Red Road, to look at what their responsibilities are and take action.

The Braid

Focussing on wellness and a reintroduction of First Nations culture, as well as extending that teaching to schools and the medical establishment, creates a strong braid that addresses the psychological, physical and spiritual aspects of the risk-taking behaviour that put First Nations
youth at risk for HCV. This approach leads to increased strength and courage among youth, parents and Elders, among family and community. It is important to focus on the courage and strength of the people. Don’t look at the deficit, look at what they have. The spirit of the youth will shine through once they feel having a sense of community, culture, and connectedness of feeling accepted as who they are from a community.

Conclusion

In order to ensure that youth and Elders have the courage to prevent HCV, we must look at the strengths of each group and build on what we know. Effective HCV prevention programs for First Nation youth will incorporate the three aspects of mind, body and spirit, as all three of these elements have been damaged for the youth whose culture is surviving risky lives. To strengthen First Nations culture, these programs should address the traditional hierarchy of consulting the Elders first. Therefore, in order for them to be successfully involved, the Elders need to be educated about HCV, as do the parents. This training can occur in many different ways, for example, at health fairs, workshops and traditional ceremonies, while youth training can take place in the community as well as in their schools. Also, youth need to feel they fit in, not with the drugs and alcohol scene, which are not the First Nation way, but by feeling ‘cool’ about their own culture, beliefs and values. This will help to prevent HCV in First Nation youth.

In closing, I offer the following quotes which comes from A Persistent Spirit (1995):

“The colonial experience and the ongoing experience of oppression have robbed Indigenous people of their spirit. Healing is a means of recovery of the spirit, and is a necessary part of the drive for self-management and self-determination” (p. v). With the healing of the spirit, which also leads to healthy communities, the following quote is added from a Regina, Planned
Parenthood, Young Women's Wellness Brochure (no date), "Because a community is only as healthy as its youth," (brochure, p. 1). The spirit is what makes us strong,
REFERENCES


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APPENDIX 1

_Braid Theory_

Developed by Lucy Barney, RN, BScN, MScN (C), 1999 ©

First Nations people and wellness; How can First Nations women heal or live well with so many health issues such as mental and physical issues? Healing does not necessarily mean to be cured of an illness, but to have the feeling of wellness. It is the ability to cope with whatever the person is experiencing. The _Braid Theory_ will explain how healing or prevention can occur.

The _Braid Theory_ consists of looking at the _Mind, Body, and Spirit_. Braids having three strands: one strand represents the Mind, another the Body, and thirdly the Spirit. When we braid our hair, it is said we are feeling proud and worthy, when we do not, we walk with humbleness. For example: we do not take care of our looks and do not fix up our hair to look attractive.

The _Mind_ (Strand) consists of everything that includes emotions, thoughts, and feelings. Usually people feel fine, but when low self-esteem, depression, loneliness, loss of identity, lower education levels, addictions, experience violence/abuse have poor emotional and mental health.

The _Physical_ (Strand) aspect of our body is being healthy, physically. Our immune system is healthy and able to fight off disease efficiently. When we do not take care of our bodies, we develop physical diseases. Examples of physical diseases include diabetes, HIV, Alcoholism, heart disease, obesity, arthritis, etc…

_Spirituality_ (strand) has been absent for some time in the First Nations community. The strengths of spirituality provides First Nations people with a sense of belonging, pride, culture, ceremony, traditional education, medicine, prayer, responsibility, respect, spirituality (as opposed to religion), etc…It is not the fact the culture was lost- but spirituality. Without
spirituality, our bodies develop illness. Therefore, braiding the mind, body, and spirit creates a healthy holistic person. The Braid Theory can be used as a framework for healthcare providers.
APPENDIX III A

Informed Consent: youth

Invitation for you to participate in a study called,

“A Culturally Relevant First Nation youth Prevention Program for Hepatitis C”

The Researcher and Study Purpose:

You are invited by Lucy Barney, Researcher, of the Statlimx Nation, Masters of Science in Nursing student at the University of British Columbia to participate in the development of an First Nations youth Hepatitis C Prevention program. This prevention program will be tested in an First Nations community with youth once completed.

Process:

Lucy Barney, Researcher will be leading two interviews. The maximum time for each participant will be two hours. The interviews will be on a “one-to-one” basis that will take approximately one hour each. The researcher questions pertain to answering the following: “How can education of First Nation youth regarding the prevention of Hepatitis be culturally relevant?” Also, what they view a culturally relevant First Nations Prevention Hepatitis C Program could look like? The second interview will be an opportunity to clarify the information from the first interview and to gain some more data. The second interview will take approximately one hour. The object of the interviews to obtain knowledge from the First Nation youth and Elders on their views of what a culturally relevant Hepatitis C prevention program could look like.

Confidentiality:

The interviews will be tape recorded and transcribed. No one else will have access to this data but the researcher, Lucy Barney and her Thesis Committee from the University of British Columbia who include: Supervisor, Dr. Joy Johnson (thesis Chair), Margaret Osborne, Associate Professor, and Gail Butt, Adjunct Professor. The data will be kept for seven years in a locked cabinet by the Researcher and then destroyed/erased. The research data will be used for teaching purposes, presentations in scholarly conferences, and in publications in scholarly journals and will also be piloted in an First Nations community. No names will be used on the publications or presentations.
APPENDIX III B

Informed Consent: Elders

Information and Invitation for you, as an Elder to provide guidance and to participate in a study called,

“A Culturally Relevant First Nations youth Prevention Program for Hepatitis C”

The Researcher and Study Purpose:

Lucy Barney, Researcher, of the Statlimx Nation, Masters of Science in Nursing student at the University of British Columbia invites and requires permission for you to participate in the development of an First Nations youth Hepatitis C Prevention program. This prevention program will be piloted in an First Nations community with youth once completed and submitted for review by the Behavioral Research Ethics Board before it is pilot tested. This thesis and research is for Lucy Barney’s completion of her Masters of Science in Nursing program (Graduate Degree).

Process:

Lucy Barney, Researcher will be leading two interviews, which will take the maximum time of two hours. The first interview will be on a “one-to-one” basis, which will take approximately one hour. The second interview will clarify what was said in the first interview and the opportunity to add any further information you wish. The second interview will also take approximately one hour. The object of the interviews is to obtain knowledge from the First Nations youth and Elders on their views of what a culturally relevant Hepatitis C prevention program could look like.

Confidentiality:

The interviews will be tape recorded and transcribed. No one else will have access to this data but the researcher, Lucy Barney and her Thesis Committee from the School of Nursing at the University of British Columbia:

- Supervisor, Dr. Joy Johnson (Thesis Chair),
- Margaret Osborne, Associate Professor
- Gail Butt, Associate Professor

The data will be kept for seven years in a locked cabinet by the Researcher and then destroyed. The research data will be used for teaching purposes, presentations in scholarly conferences, and in publications in scholarly journals and will also be piloted in an First Nations community. No names will be used on the publications or presentations.
APPENDIX III C

Easy to Understand Informed Consent Letter

Information and Invitation for you to participate in a study called,

“A Culturally Relevant First Nation youth Prevention Program for Hepatitis C”

Introduction of the Researcher and what the Research is about:

Lucy Barney, Researcher, of the Statlimx Nation, a student at the School of Nursing (Masters of Science Program), University of British Columbia, invites and requests your permission to help in the development of recommendations for a First Nation Hepatitis C Prevention program. The recommendations will be given to First Nation communities with youth once completed and submitted for review by the Behavioral Research Ethics Board. This thesis and research is for Lucy Barney’s completion of her Masters of Science in Nursing program (Graduate Degree).

Process: How I will do this research

Lucy Barney, Researcher will be leading two interviews, which will take about two hours. The first interview will be on a “one-to-one” basis, which will take approximately one hour. The second interview will provide an opportunity to clarify what was said in the first interview and for you to be able to add more information if you choose. The reason for the interviews is to get knowledge from the youth and Elders on their ideas of what a culturally relevant Hepatitis C prevention program could look like.

Confidentiality: No one will see or hear your interview information

The interviews will be tape recorded and transcribed. No one else will see or hear the tapes or transcribed information but the researcher, Lucy Barney and her Thesis Committee from the School of Nursing at the University of British Columbia:

- Supervisor, Dr. Barbara Paterson (Thesis Chair),
- Margaret Osborne, Associate Professor
- Gail Butt, Associate Professor

The information will be kept for seven years in a locked cabinet by the Researcher and then destroyed. The information and recommendations will be used for teaching purposes, presentations in health conferences, and in journals. No names will be used on the publications or presentations.

Consent to participate: Permission to participate
APPENDIX IV

Guiding Questions

The interview should last approximately one hour. The second interview will last approximately the same, but the questions will be mainly follow up and clarification of information.

I will start with questions of gaining trust and to alleviate any discomfort that may be present. This will give me a sense I whether or not they have had any cultural teachings in the past. I will let the participants know that I would like to learn from them but that it may sound stupid, but will help to make recommendations for an First Nation prevention program for HCV.

1. Tell me a little bit about yourself. Where are you from?
2. Were you taught any First Nation cultural teachings?

Starting with a probing Question, and if follow-up is required, I will do this.

3. Do you know of anyone with Hepatitis?
4. What do you people do about Hepatitis?
5. What do you think are ways you might “catch” Hepatitis?
6. Why do you think First Nation youth take these risks?
7. Is there any suggestions you have on ways of preventing HCV in First Nation youth?

The Elders in collaboration with the researcher will determine the questions. They will determine the questions to answer the following overarching research questions:

1. How can education of First Nation youth regarding the prevention of Hepatitis C be culturally relevant?
2. Why do you think First Nation youth are discouraged and turn to risky behaviors?
3. What is the strength of First Nation youth or First Nation people that might keep them strong?
4. What is their idea of what a culturally relevant First Nations Prevention Hepatitis C Program could look like?
APPENDIX V

Locating self: Who am I and where am I from?

G. Lucy Barney, Lillooet Nation, RN, BScN, (Masters C, University of British Columbia).

Biography

Lucy is from the Lillooet Nation, mother of two boys and a Traditional dancer who incorporates her traditional knowledge with her current work as the Program Manager of Chee Mamuk, First Nations Program, BC Centre for Disease Control. Knowing the Western Medicine of health and the traditional practices of First Nations peoples view of wellness, Lucy developed the “Braid Theory,” which looks at the body, mind, and spirit.

Lucy received her Registered Nurse Diploma through Langara College, 1996 and her Bachelor of Science in Nursing from the University of Victoria in 1997. She is currently working on her Masters of Science in Nursing at the University of British Columbia, specializing in Leadership, and First Nations Health. Thesis: Prevention Program for First Nation youth on Hepatitis C.