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Engaging the Liminal: Indigenous Perceptions Within the Healthcare System

Karen J. Lottis

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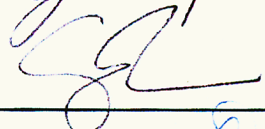
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**ENGAGING THE LIMINAL:
INDIGENOUS PERCEPTIONS WITHIN THE
HEALTHCARE SYSTEM**

by

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B.S., Nursing, Seattle Pacific University, 1994
M.S., Nursing, University of New Mexico, 2004

DISSERTATION

Submitted in Partial Fulfillment of the
Requirements for the Degree of

Doctor of Philosophy in Nursing

The University of New Mexico
Albuquerque, New Mexico

June 30, 2011

DEDICATION

I dedicate this study to the First Nation communities along the coast of BC and throughout Canada, as well as the Native American communities of the U.S. May it prompt further opportunities for expression, empower tribal development of healthcare priorities, and creation of a stronger health system in which every person receives high quality and equitable healthcare.

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To my parents, brother and sister — Bill and Sandy, Jim and Kristy, I love you and say thank you a thousand times over. The unwavering support and hours listening while I rambled on about one philosophy or another, or willingness to read yet another rendition of a paper kept me on track. Regular phone calls reminded me that there was a light at the end of the tunnel, and my family would still be there!

To my beloved children, Mark and Erin, and partner, Bob — each of you have been consistently present to the pain, evolution and joys that this process entailed. Thank you. I love you each — deeply.

Karen Lottis

EXPLORING THE LIMINAL: INDIGENOUS PERCEPTIONS WITHIN THE HEALTHCARE SYSTEM

by

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ABSTRACT

It is well documented that there is decreased access and utilization of healthcare services by minority populations. The purpose of this study was to explore experiences with, and views of, the healthcare system among remotely situated First Nations people of coastal British Columbia (BC), to shed light on elements considered crucial to healthcare delivery. The study was conducted as a critical ethnography with an underlying framework of phenomenology and critical social theory. Multiple sources of data collection included private interviews, community observations, conversations, celebratory gatherings, participant-observer field notes, and the art and music of the people involved. Multiphase data management consistent with immersion and crystallization offered reflective/emotional, structured and synthesis levels of analysis, providing a rich aggregate of themes.

Findings revealed that individuals who had developed relationships of trust with providers, or whose family members acted as advocates in healthcare encounters reported a higher level of satisfaction with the healthcare they received. However, many voiced perceptions of prejudice and stigmatization, believing healthcare to be of a lower quality than that received by non-Aboriginal BC residents. These findings were deeply embedded contextually and were framed by the legacy of a colonial past, ongoing 'civilized oppression,' and the socioeconomics of isolated living.

KEYWORDS: Aboriginal, indigenous, remote, isolated, healthcare, oppression, stigmatization, relationships of trust, critical ethnography, phenomenology, critical social theory.

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CHAPTER 1

Purpose of the Study

The purpose of this study was to explore experiences with, and views of, the healthcare system among remotely situated First Nations people of coastal British Columbia (BC), to shed light on elements considered crucial to healthcare delivery. It is well documented that minority populations receive decreased access to quality healthcare (Andrulis, 2003; Coburn, 2004; Facione & Facione, 2007; Kennedy, Mathis, & Woods, 2007; Olekalns & Smith, 2005). Tarlier, Browne, and Johnson (2007) noted that for indigenous members of remote communities, limited access confounded by a paucity of adequately prepared healthcare providers, frequent turnover of personnel, and limited secondary/tertiary support creates significantly fragmented care. The resultant patient view is one of ambivalence toward, if not outright distrust of, the provider and/or the healthcare system (Lauder, Reel, Farmer, & Griggs, 2006; Lewicki, McAllister, & Bies, 1998; Vasas, 2005). The literature suggests that encounters will be unsuccessful if trust is not present (Andrulis; Kennedy et al.; Olekalns & Smith). Further, those who mistrust the system may not present at all until acutely ill (Andrulis).

Having spent much of my early life in BC among First Nations people, I have been aware of the profound disconnect that frequently occurs between individuals and the medical system. Recognizing that much of this disconnect has been due to lack of direct input and control of programs by indigenous members themselves, I became curious as to the views held by First Nation people regarding healthcare. Choosing a methodology of

critical ethnographic inquiry, I sought to engage and learn from individuals in the space between worldviews and cultural constructions. It is from within this spatial transitional phase that culture, power, and politics can be creatively re-imagined (Hall, 2007; Shome, 2003). I conducted narrative interviews in community settings to promote trust and empower participants. By deliberately forming quality partnerships with First Nation individuals, I expected this investigation to have a two-fold effect: (1) to empower people to claim control over elements of healthcare considered essential to their wellbeing, and (2) to impact healthcare policies and healthcare delivery mechanisms.

Specific Aims

To explore and chronicle the perspectives and experiences of First Nation individuals, the Specific Aims of the study were:

- 1) to describe how First Nation people view their healthcare,
- 2) to explore how past experiences and views of healthcare influence presentation and care utilization,
- 3) to compare First Nations members' views of care received in remote outpost clinics versus care received in distant urban center settings,
- 4) to explore the impact of a healthcare provider's cultural awareness on the level of healthcare system engagement by First Nation members, and
- 5) to explore the degree to which First Nation individuals integrate traditional healing with the Western healthcare system, and the prevalence of discussion and reaction to such integration with the healthcare provider.

A section on Significance of Socioeconomic Indicators and Historical Background follows to provide a context for the chapters on Literature Review, Methods, Findings/Results, and Conclusions/Implications. The characteristics of study participants, as well as their geographic location, history, cultural norms, and health status indicators depict a simultaneous blend of beauty and deprivation, of wealth and disparity, of completeness and inequity. A full appreciation of these factors is necessary to understand many of the challenges noted in the critical review of relevant literature, and to provide a rationale for the particular research methods chosen.

Significance of Socioeconomic Indicators

To understand the challenges of ensuring adequate healthcare distribution, it is important to appreciate not only the geographic isolation of the BC First Nation communities, but also the socioeconomic disparities associated with remote or rural living. BC, with a land mass of 944,735 km², is larger than the total areas of Washington, Oregon, and California combined, and has diverse ecosystems. The rugged Pacific coastline traverses over 27,000 km, includes deep fjords and approximately 6,000 islands, most of which are uninhabited (Tourism BC, n.d.). Appendix A provides a map of the Canadian province (BC Stats, n.d.).

The term “Aboriginal” is an inclusive term used for descendants of the first inhabitants of North America and is synonymous with the term “Indigenous,” and I will use each consistent with the studies or reports reviewed. The terms “Aboriginal” and “Indigenous” are broad in nature and include a wide range of cultural identification and

practices specific to each unique nation/tribe. In Canada, the term “Aboriginal” includes First Nations (FN), Inuit, Métis (FN and European ancestry), and North American Indian (BC Office of the Provincial Health Officer, 2001).

In 2006 the Aboriginal population, just over 196,000 of the 3,868,875 total population of BC, with a mean age of 26.8 years, represented over 30 nations and 197 communities (BC Stats, 2007). Aboriginal people living along the BC coast are included in the ‘Northwest Coast’ subset, one of the three geographic cultural areas identified in BC, which encompasses northern California to Alaska, with abundant marine and coastal rainforest resources. There are over 20 major ethnic groups of the Northwest Coast in BC, and some tribes have remained living on ancestral land thus representing a certain level of continuity. However, the Department of Indian Affairs has relocated numerous others, with significant reduction in their resources. For the majority of coastal bands, reservation land is geographically isolated, creating profound challenges in delivery and access to services.

Central coast socioeconomic indicators.

In BC, demographic information is accessed through specific regions, and no specific information includes the NW Coast. Therefore, I have provided statistics for the central coast of BC, as they are representative of the geographically isolated coastline. Participants, however, were not restricted to the central coast region.

According to Statistics Canada, the total central coast population as of 2001 was 3,780, with a population density of 0.2 per km² compared to the total BC density of 4.2

per km². Of this central coast population, 2,240 individuals self-identified as Aboriginal, 51% were males and 49% were females. The main sources of livelihood along the central coast region are forestry, fishing, administrative services, and ecotourism (Statistics Canada, 2002).

Socioeconomic status indicators such as median income and education serve as determinants of health; a lower income and educational attainment creates cycles of poverty that affect every aspect of life. In 2000, the median earnings for coastal Aboriginals who received government subsidies was \$21,403, while the median earnings for coastal Aboriginals who did not receive government subsidies was \$16,385. Also in 2000, the median BC Aboriginal household income of \$29,150 compared unfavorably to the median BC non-Aboriginal household income of \$46,802 (Statistics Canada, 2001).

Education disparity.

Aboriginal students attending elementary and high school achieved foundation skills assessment scores (FSA) at the grade levels of four, seven, and ten, in all but un-certified, band-operated schools. Cowley and Easton (2004), stated that “On average, Aboriginal students’ results on these examinations are poor both in absolute terms and relative to those of non-Aboriginal students in all subject areas, at all grade levels, and on all test sittings” (pp. 10-11). It follows that consistently low FSA scores portend a high dropout rate from high school (Figure 1). In 2006 only 24.4% of Aboriginal people living in BC had completed a high school certificate or equivalent; 15.4% had obtained an

apprenticeship or trade certificate; 4.9% had earned a bachelor’s degree; and, 0.9% had earned a certificate or diploma above the bachelor’s level (BC-PHO, 2009, p. 250).

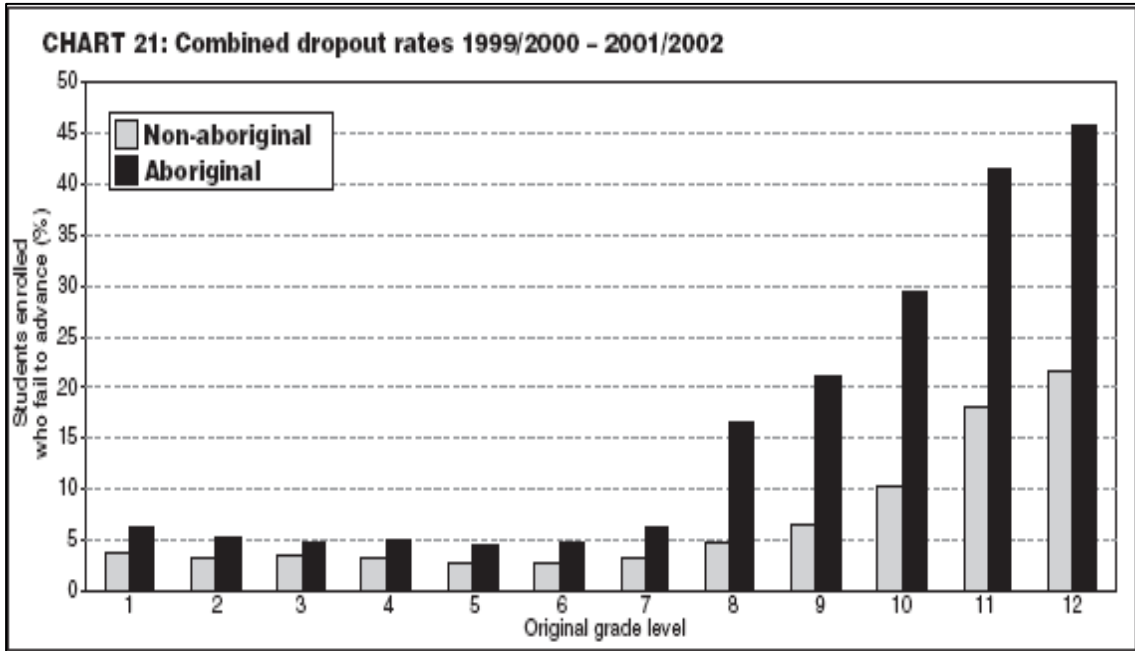


Figure 1. Cowley & Easton (2004, p. 18).

Socioeconomic disparity and health.

The socioeconomic disparity evidenced by education and income statistics argues for examination of health indicators through a critical lens. Coburn (2004) claimed that not only income inequality but also, “Social hierarchies are said to produce disease because of the poor self-esteem associated with lower status which, in turn, through psycho-neuro-biological pathways, negatively influences health” (p. 42). The Provincial Health Officer’s annual reports document the health disparities concomitant with the lower socioeconomic situation of BC’s First Nation people (BC-PHO, 2007). These reports provide statistics in potential years of life lost standardized rates (PYLLSR) for all

indicators including diabetes, cancers, HIV disease, suicide deaths, alcohol-related deaths, and smoking-attributable and drug-induced deaths (Figure 2).

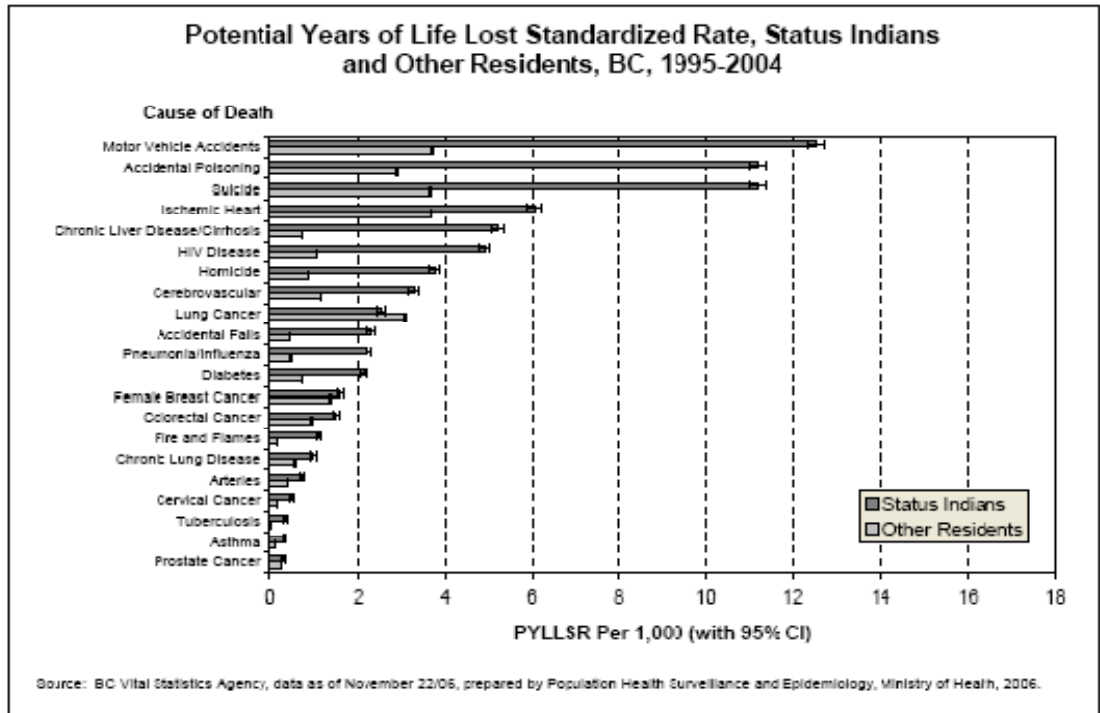


Figure 2. BC Office of Provincial Health Officer (2007, p. 9).

Examination of the epidemiologic data reveals a disturbing picture: Status Indians¹ bear a disproportionate burden in chronic disease morbidity/mortality and in preventable hospitalizations. The overall life expectancy for Status Indians is 74.9 years versus 80.7 for the non-Indian British Columbian (BC-PHO Annual Report, 2009, Chapter 4). Further, examination of this report illustrates consistently higher morbidity statistics, associated with diabetes mellitus (Figure 3), osteoarthritis, chronic obstructive

¹ Both Status Indians and Non-Status Indians are considered First Nations. Status Indians are entitled to the provisions of the *Indian Act*. Non-Status Indians either do not meet registration criteria or have chosen not to be registered. (BCPHO, 2001).

pulmonary disease, and preventable hospitalizations among Aboriginals than among Other Residents. The ratio for Aboriginal mortality related to medically treatable diseases was 3.8 that of Other Residents (BC Stats, 2007, p. 46).

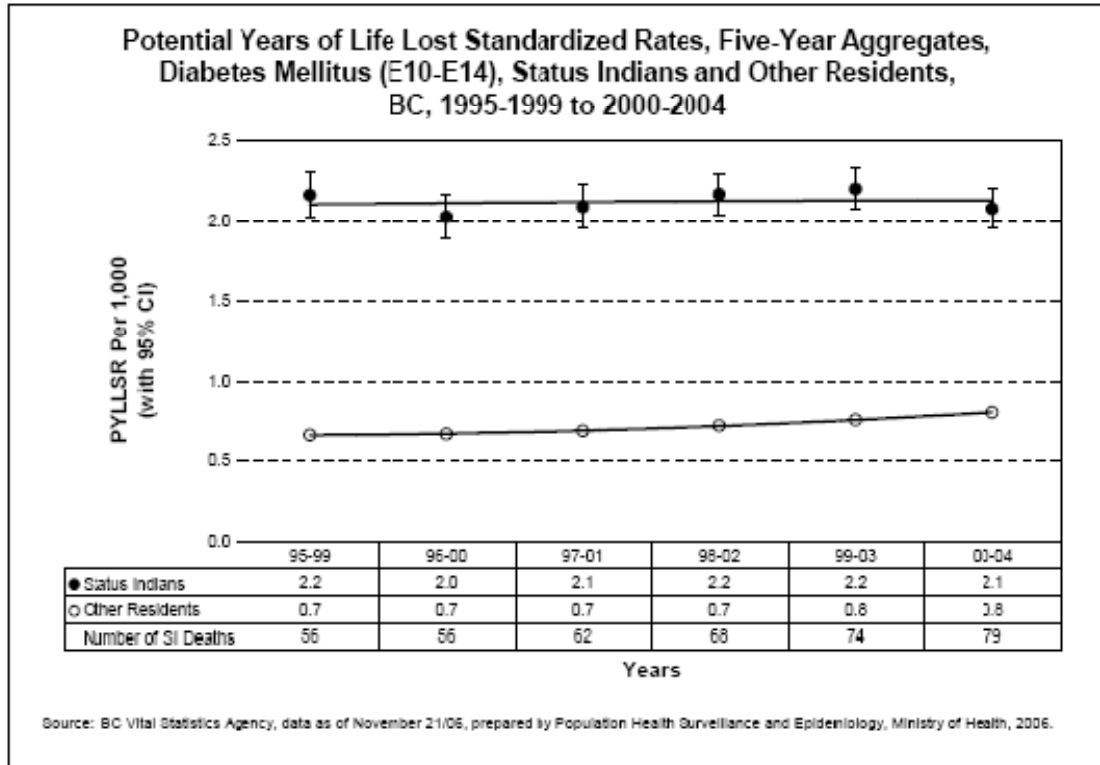


Figure 3. BC Office of Provincial Health Officer (2007, p. 11).

Equally compelling are the effects of underlying social disorders evidenced by the high number of alcohol-related deaths (Figure 4), suicides, which were the third overall cause of death for Status Indians (Figure 5), and HIV mortality rates (Figure 6). The rapidly widening gap between Aboriginal and Other Resident experience speaks to increased Aboriginal vulnerability and lack of access to appropriate treatments (BC-PHO, 2007).

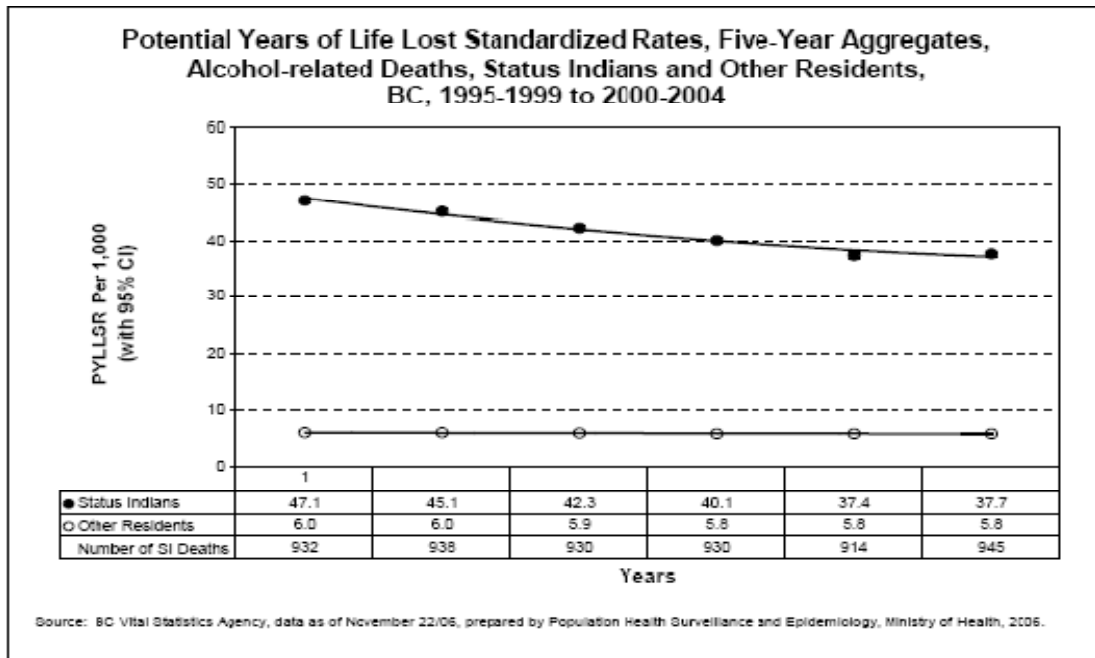


Figure 4. BC Office of Provincial Health Officer (2007, p. 15).

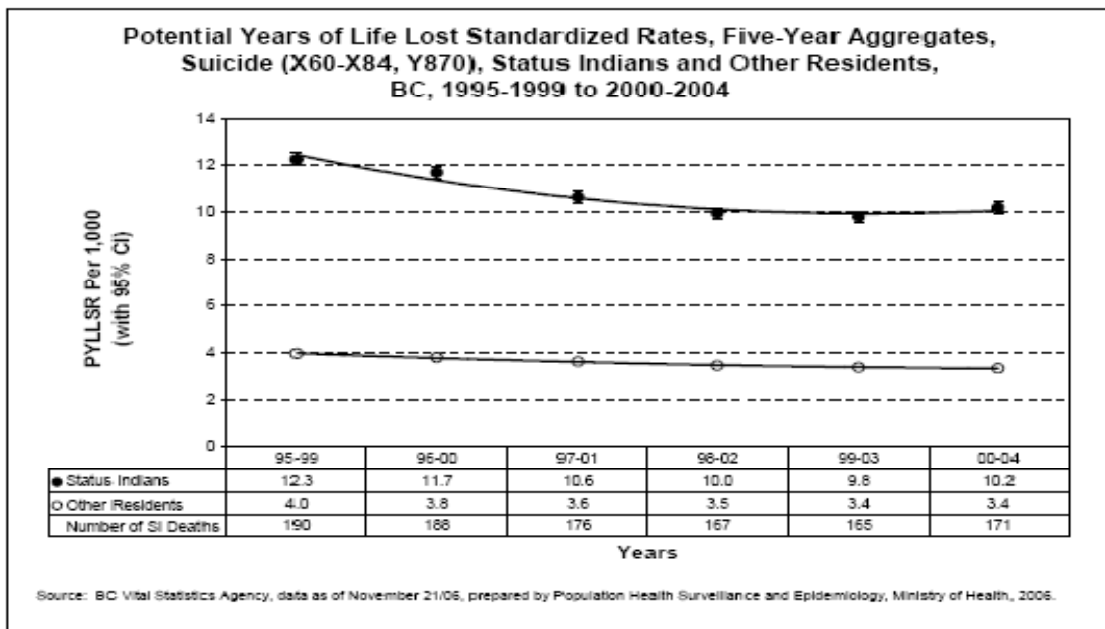


Figure 5. BC Office of Provincial Health Officer (2007, p. 14).

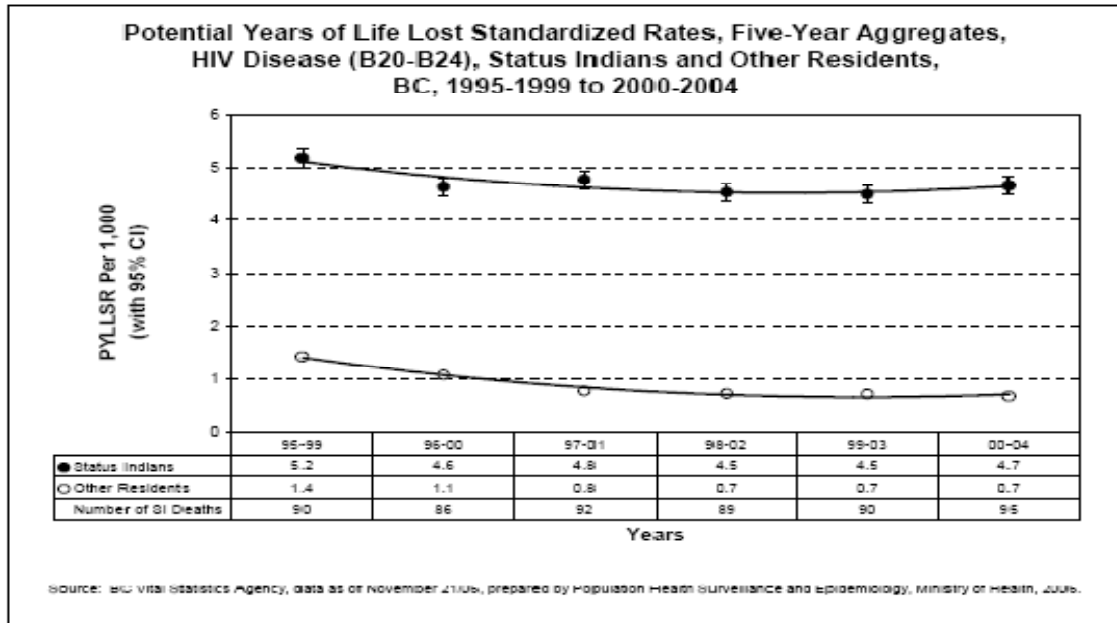


Figure 6. BC Office of Provincial Health Officer (2007, p. 13).

There is full recognition by the provincial healthcare system for the much-needed culturally appropriate medical and mental health services, yet access and use of these resources is decreased compared to non-Aboriginal residents. According to data from the Ministry of Health Services, in 2006/2007 over twice as many Status Indians received a hospital discharge relating to a mental health condition than other residents, and post-discharge follow-up with mental health services is significantly lower for Aboriginal clients, (BC-PHO, 2009).

For many who relocate, the separation from their land and extended family creates crisis. Increasing numbers of FN individuals are living off the reservation (see Figure 7), the reasons for which appear complex. In a competitive urban environment, efforts to obtain affordable housing and employment can be challenging. Compounding these challenges, data reveal increasing trends in tuberculosis, HIV disease, and

homelessness among relocated Aboriginals. Cases of tuberculosis contracted by Aboriginal people living off-reserve were 38.1 per 100,000 versus 19.9 per 100,000 among the population on-reserve (BC-PHO, 2009, p. xxxv). This same report estimated that Aboriginal people represented over 30% of the homeless population, yet accounted for only 2% of the Greater Vancouver Regional District population (BC-PHO, 2009, p. 160).

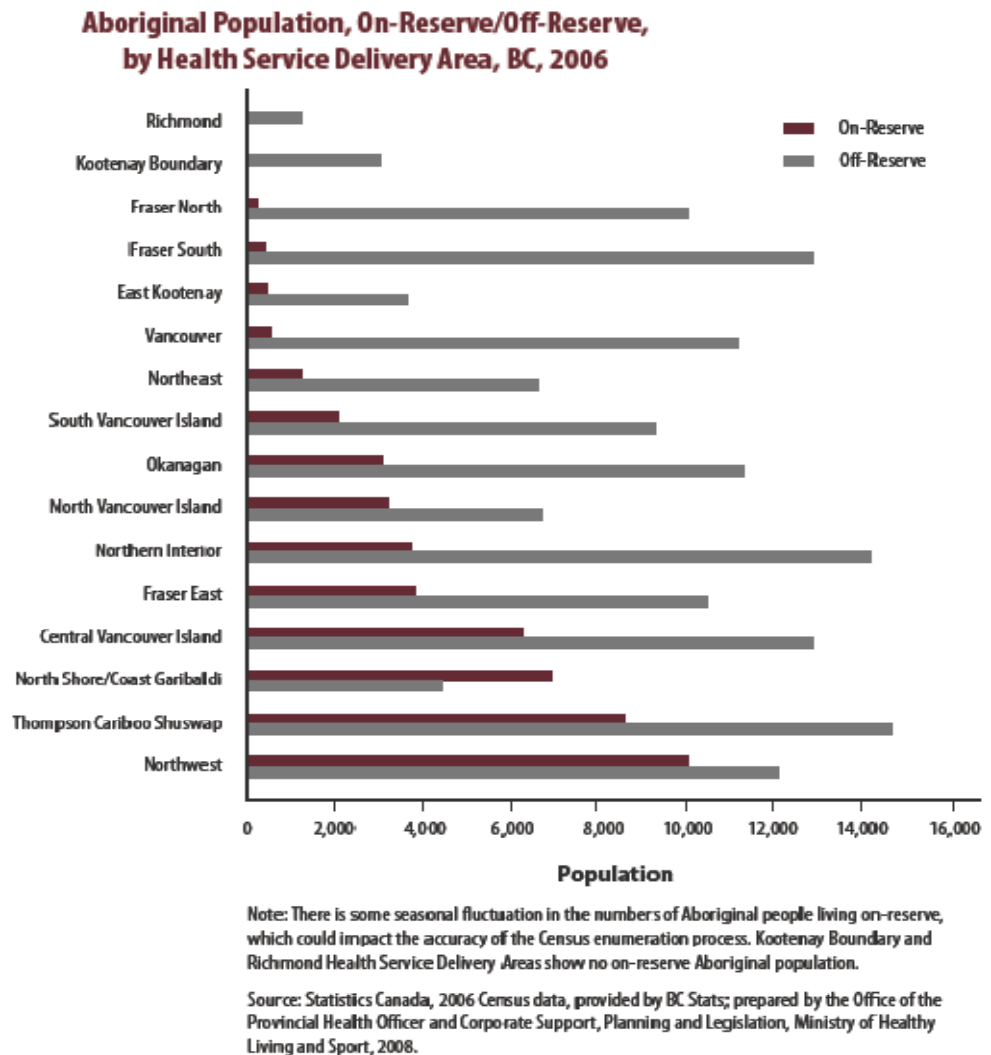


Figure 7. BC Office of PHO (2009, p. 22).

There have been improvements in many indicators over the past decade in BC, yet the gap between Status Indians and Other Residents remains significant. *The Health and Well-being of the Aboriginal Population in British Columbia, Interim Update*, by the BC-PHO (2007), confirmed that across all measures examined “Status Indians die at earlier ages and at greater rates than other BC residents” (p. 17). The report also acknowledged that, “there is a persisting and broadly based gap across multiple indicators that cannot be explained by some specific genetic risk alone, as the causes are varied and rooted in socioeconomic disparities and cultural disruption” (p. 17). Appreciation for these disparities must come from contextualization of the complicated history.

Historical Framework

To understand the continuing gap in quality of life between First Nations people and others, these socioeconomic disparities must be examined in light of the historical oppression and suppression of the First Nation people and their subsequent loss of cultural traditions.

Living off the land.

The pre-colonial population of British Columbia numbered between 300,000 and 400,000 and was home to the most concentrated numbers of aboriginal people north of Mexico (Tennant, 1990). At the time of contact, there were 30 distinct nations in BC, each with a specific language, culture, territories, and government, and each as unique from the others as were the various countries of Europe (Tennant). These communities thrived because of their highly structured society and political leadership, and because of

an abundant natural resource — red cedar. With the wood from the red cedar, Aboriginal people built the world's largest dugout canoes, affording them access to marine and land resources not otherwise available. These resources, along with the common trade language of *Chinook*, provided opportunities for trade up and down the coastline. They used cedar to build plank houses to protect large family groups through the winter (Tennant), as well as for clothing, baskets, and objects of art and ritual (BC-PHO, 2009).

The traditional coastal diets were exceedingly varied, high in protein and poly-unsaturated fat, with preserving methods that maintained high quality and sufficiency throughout the winter. Foods included many types of fish, marine mammals, seaweed and shellfish, seagull eggs, a variety of game, and over 120 types of plants, roots, and berries (Kelm, 1998). They harvested oolichan, a small, extremely high-fat, high-vitamin fish, and while some was eaten fresh and dried, the majority was rendered into 'grease' which to this day remains a prized commodity. Over the last century, however, the decline of fish and shellfish, shrinking land resources, and competition with commercial and sport fishing interests created particular hardship for the isolated coastal groups with limited access to other fresh food sources. Because of the high shipping costs, communities must now pay exorbitant prices for fresh food, influencing the gradual acceptance of highly processed, less nutritional food substitutes.

Political control and assimilation.

Bands created stability and continuity in tribal leadership through hereditary succession of clan chiefs, typically four in each tribe, who began their training at an early

age. Chiefs held elaborate feasts called *potlatches*, during which they bestowed gifts on all members of the community. This not only assured continuation of the chief's prestige and status, but also maintained circulation of wealth (Tennant, 1990). In large part, this political system remains in use along the Northwest Coast by Aboriginal people, although there are occasions when the tribe will choose the next chief for his or her promise as a leader rather than for their lineage.

White colonizers did not exert full control in BC until 1890, after which the Aboriginal population declined dramatically. By 1929, endemic disease and deaths involving alcohol and weapons acquired through contact with European settlers shrank the population to a low of 22,605 (Kelm, 1998). This devastating population loss had an insidious secondary impact — the disappearance of a way of life. Clans maintained proprietary rights to many of their names, rituals, art designs, songs, and stories. But the epidemics of smallpox, influenza, plague, cholera, typhus, and measles that swept the region buried the cultural knowledge along with the dead (BC-PHO, 2009; Tennant, 1990).

Population attrition accounted for loss of traditions and ways of knowing, but intentional and systematic attempts to eradicate Native culture and language, in order to force assimilation exacerbated the process. With First Nation populations dwindling, during the period from 1912 through 1916, the McKenna-McBride Commission reduced the size of lands that had been appropriated for the “use and benefit of Indians” (Indian Cut-Off Lands Disputes Act, 2009). In some cases the size of these cut-offs were significant.

They added to the ongoing *adjustments* and *resurveys* that began in the late 1800's and continued through the 20th century (Ware, 1974). According to Kelm (1998), colonization's most devastating impact occurred within the first half of the 20th century, and it continues to leave a legacy of disruption, displacement, and generational trauma.

The introduction of residential schools across North America witnessed the forced removal of Aboriginal youth from their families. Placed in dormitories, these youth had to renounce their traditional dress, names, and language. The first residential school in BC opened in 1863 and did not close until 1984 (BC-PHO, 2009). In addition, the Canadian government used legislation, the Indian Act of 1876, to control Aboriginal people until they were considered to have obtained full assimilation (Hick, 1998). Essentially, all Aboriginal people became wards of the state (Canada in the Making, n.d.). By the 1920's, attendance in a residential boarding school was compulsory for all youth (BC-PHO).

The province of BC had the most residential schools in Canada. Of the 80,000 total Canadian residential school survivors, an estimated 35,000 survivors still reside in BC. Documentation chronicles the cultural disruption, loss of family identity and original languages, and physical, sexual, psychological, and spiritual abuse suffered by many school residents (BC-PHO, 2009; Indian and Northern Affairs Canada, [INAC] 1996). The lingering effects of these attempts at assimilation remain in evidence. Mental health symptoms similar to post-traumatic stress disorder, substance abuse, suicide, and domestic violence impact not only the residential school survivors but also their family members (BC-PHO; INAC).

Current Trends Toward Reconciliation

In the last two decades, the Canadian government has made progress in recognizing the damages caused to Aboriginal people, and in moving toward reconciliation. These include:

- 1) an official apology by Prime Minister Harper in 2008 for the government's role in the residential schools (Appendix B),
- 2) official support in the reclamation of culture through language skills, arts and other traditions (BC-PHO, 2009; INAC, 1996),
- 3) support for Aboriginal people in higher education health sciences through the University of British Columbia (Institute for Aboriginal Health, n.d.),
- 4) the Transformative Change Accord signed in 2005 which works toward (p. 2):
 - a. closing the gap between First Nations and other Canadian residents in the areas of health, education, housing, and economic opportunities over a 10-year period,
 - b. reconciliation of Aboriginal rights and title,
 - c. establishing a relationship of mutual respect and recognition, and
- 5) the Tripartite First Nations Health Plan signed in 2007, that continues to move toward tribally-controlled healthcare administrations, and closure of the healthcare gap (Ministry of Aboriginal Relations and Reconciliation, 2007; BC-PHO, 2009).

Despite these overtures, a multitude of socioeconomic, physical, and emotional factors present obstacles to change. For example, the paucity of providers adequately prepared to staff outpost clinics or hospitals challenges healthcare delivery to remote areas. This creates a revolving-door style of care that is not conducive to continuity or to building healthy provider-patient relationships. It was in response to this phenomenon that the University of British Columbia established the Institute for Aboriginal Health in 1998. The institute's focus is on successful attainment of higher education in health sciences among Aboriginal students. Its prevailing philosophy is that no one will better solve the issues of the Aboriginal peoples than Aboriginal people themselves.

Without a doubt, this is the long term answer — self-governance and self-sufficiency. However, recognition of the long history of oppression and current overall socioeconomic status requires that mainstream society take responsibility for the abusive history. In describing findings from their work with the Global Rights coalition of youth activists, Fine, Tuck, and Zeller-Berkman (2008) stated, “We recognized that the ripples of globalized oppression take varied forms — alcoholism, domestic violence, hopelessness, economic indigency — none easily reduced to a simple descriptor of discrimination” (p. 162). In *Pathways to Health and Healing*, the report from the BC-PHO (2009), Chief Clarence Louie of South Okanagan stated:

Our major weakness, and it is considerable, is all the leftover dysfunction from our colonial past — the control exerted over us by the Indian Act, the administration of our affairs by the Department of Indian Affairs, family breakdown, the cycle of welfare, the victimization syndrome, [and] the dependency syndrome are still with us today. We are like a Third World country trying to emerge from a

colonial past. After 100 years of abuse by the Federal and Provincial governments, many of our people are not ready for work (p. 28).

One method of taking responsibility is to create Indigenous – colonizer collaborations. Smith (1999) spoke of the Western tendency to exert “positional superiority” (p. 58). It is imperative that we reflect on the spatiotemporal dynamics of culture and how these define the places we occupy within our social realities — how we dominate or share relational space. Partnerships take many forms, but in the Indigenous — colonizer collaboration, both must be willing to explore and to work this liminal zone surrounding the hyphen. Jones and Jenkins (2008) described this hyphen as “a bridge, a moment of translation ... for the colonizer researcher who gives voice to the oppressed indigenous person enabling a direct and sympathetic hearing from others (p. 474). These authors posited “The hyphen is nonnegotiable” (p. 475). The hyphen as a bridge is only the first step. The ultimate significance of these partnerships is really the implied circle that surrounds this hyphen. This way of seeing from all perspectives requires what Kincheloe and Steinberg (2008) defined as *multilogical* insights.

In the report of the Royal Commission for Aboriginal Peoples (1996), Marlene Buffalo stated “Poverty, poor health, under-education and high mortality rates all indicate the long-term impacts of the colonization mind-set. It is the Aboriginal peoples' conception of their needs and interests which must be the starting point — the real [meaning] of the term 'self-determination'” (INAC: Lost Earnings and Production, ¶5). To observe, to listen, *and* to hear perceptions of needs and interests, to acknowledge the historicity of

experience in the formation of current attitudes, and to discuss the creation of possible solutions, this is what I seek to accomplish through the use of a critical ethnography.

Theoretical Foundations

The foundational philosophy of this study is phenomenology, influenced by later philosophers such as Merleau-Ponty, Gadamer, and Habermas. Critical social theory as a paradigm informs the methodology of critical ethnography and narrative inquiry throughout this study.

Phenomenology.

Phenomenology supposes that the embodied experiences and resultant perceptions determine the essence of meaning (Madison, 2005; Merleau-Ponty, 1958/2006). Madison asserted, “Whatever appears in the human mind as it manifests itself in consciousness is the phenomenological project” (p. 57). Critique of early phenomenology included the self-absorbed or *privileged* nature of *being*, and a shift took place toward relationship with Other. Recognition of our inter-connectedness expanded application of phenomenology into relational fields. Merleau-Ponty (1958/2006) stated “Your abode is your act itself. Your act is you ... You give yourself in exchange ... Man is but a network of relationships, and these alone matter to him” (p. 530). He believed that this entailed “communication between one consciousness and another in one and the same world” (p. 411). When examined in the context of marginalized populations, our concept of “one and the same world” however, may often be stretched to an uncomfortable degree. In this

setting, true communication requires a willingness to search the unknown, to ask questions that may upset previously held convictions, and to entertain new possibilities.

Gadamer (1976) considered hermeneutics, which recognizes underlying, non-observable meanings to be at the heart of many interactions, to be requisite in exploring situations not readily definable. It requires each party to interpret in such a way that it creates a “fusion of horizons” between respective realities. Communication in the purest sense is an act of interpretation. Gadamer (1975/2004) reminded us that “Without such openness to one another there is no genuine human bond. Belonging together always also means being able to listen to one another” (p. 355). Further, “To reach an understanding in a dialogue is not merely a matter of putting oneself forward and successfully asserting one’s own point of view, but being transformed into a communion in which we do not remain what we were” (p. 371). Transformation through communion demands critical examination of the part each plays in promoting/allowing continued oppression by dominant powers such as culture, religion, economy, education, or politics. Real communication then requires incorporating justice-based ethics into our relationship with Other.

Jürgen Habermas suggested an action-oriented approach to illustrate the importance of justice and communication between people. Habermas (1987) described a model of action that demands a stance that is no longer *privileged*:

Fundamental to the paradigm of mutual understanding is, rather, the performative attitude of participants in interaction, who coordinate their plans for action by coming to

an understanding about something in the world...The latter is structured by the system of reciprocally interlocked perspectives among speakers, hearers, and nonparticipants who happen to be present at the time (p. 296-297):

Each of the above philosophers considered it essential to gather meanings relating to human perception, and to seek genuine communication and reflective understanding from the context of one's own previous experience. Entering into such a transformative relationship, particularly while exploring perceptions of a historically-oppressed population, requires a justice-based paradigm. Thus critical social theory informs this study.

Critical social theory.

Critical social theory is a transformative ideology which opposes positivism, asserts that domination is structured by the complex interactions within the larger social context of privilege, and argues for the possibility of a better future, rid of oppression and exploitation through political and social action (Agger, 1998; Kincheloe & McLaren, 2003). To create a climate of transformation, Freire (1970/2000), believed the only solution is to enter into a "permanent relationship of dialogue" (p. 68) that expresses a collective consciousness. In this consciousness, activist and oppressed are both "Subjects, not only in the task of unveiling that reality, and thereby coming to know it critically, but in the task of re-creating that knowledge" (p. 69). He affirmed that, "A deepened consciousness of their situation leads people to apprehend that situation as an historical reality susceptible of transformation" (p. 85). This level of engagement, particularly through critical ethnography and narrative inquiry, framed by cultural safety, allows

individuals to confront elements of their experiences and glimpse into oppressive societal boundaries.

Critical ethnography.

Ethnography is a field of research commonly used in the social sciences that combines multiple ways of knowing to describe detailed accounts of everyday life and practices in order to interpret cultural constructions (Emerson, Fretz & Shaw, 1995; Laugharne, 1995; Madison, 2005; Tedlock, 2003). However, ethnography in and of itself does not engage with the politics of injustice. For this to occur we must first situate ethnography within a criticalist paradigm. Kincheloe and McLaren (2003) stated:

Inquiry that aspires to the name *critical* must be connected to an attempt to confront the injustice of a particular society or public sphere within the society. Research thus becomes a transformative endeavor unembarrassed by the label *political* and unafraid to consummate a relationship with emancipator consciousness (p. 453).

There are two dynamic parts to the process of critical ethnography. First, there must be a willingness to move beyond neutral observation to understand the structures of power and control. Observation situated in cultural safety demands apprehending the experiences and needs of others. Second, once understood, the injustice of oppression and radically different power differentials must be confronted, which then presents a responsibility to motivate action for change (Bransford, 2006; Kincheloe & McLaren, 2003; Kincheloe & Steinberg, 2008). This is an ethical research stance that *cannot* occur without direct agreement, participation, and commitment from the local communities

involved. Madison (2005) defined this as “a meeting of multiple sides in an encounter with and among the Other(s), one in which there is a negotiation and dialogue toward substantial and viable meanings that make a difference in the Other’s world” (p. 9).

Critical ethnography techniques, therefore, require a caveat: It is important that research results remain situated within local contexts, where the communities involved retain direct input in development and refinement of research and subsequent actions.

Narrative inquiry.

Narrative inquiry is a powerful method of obtaining perspectives on the lived experience in which the participant subsequently finds meaning through both the telling and the interpreting of the interview (Elliott, 2005; Good & Good, 2000; Phoenix, 2008; Squire, 2008). Garro and Mattingly (2000) described narratives as “a place to explore cultural life as an unfolding personal and social drama” (p. 17). This unfolding drama, when examined together, allows community members to share new perspectives on their lived experience, and to place these within the larger sociopolitical context (Elliott; Good & Good; Phoenix; Squire). As Elliott observed, “Once narrative is understood as not simply descriptive but constitutive of the self, the potential of research to be a significant transformative experience must be recognized” (p. 140). She believed this methodology was congruent with giving “a voice to the most marginalized groups within society” (p. 144).

Common to Western medicine is a tendency to focus therapeutics on the “ahistorical, atemporal, and nonsocial dimensions of the medicalized body” (Good &

Good, 2000, p. 51). In contrast, narrative exploration of perceptions regarding healthcare honor experience, and allow these accounts to create personal meaning and inform the collective. Narrative inquiry situated within ethnography, with the freedom to *talk story* is particularly appropriate in an Aboriginal cultural setting. The report by the Royal Commission on Aboriginals, clarifies the role of First Nations elders:

They transmit culture and mores through action, example and oral tradition [with] stories, jokes, games and other shared activities. The experience is personal; speaker and listener share the event. Hearing stories and teachings, listeners feel the pain, the joy, the victories and defeats of their people. They reach out to one another across time. Past, present and future become one (INAC: Voices of Elders, 1996, ¶9).

Analyzing narrative accounts from within a critical ethnographic framework, exploring with, and learning from First Nation community members willing to push the boundaries of what is known provides a mechanism to confront *whitestream* prejudice and power. These endeavors hold the potential for all participants involved to reach new levels of understanding and, as Cannella and Manuelito (2008) stated, “Attempt to create transformative solidarities that can generate ‘unthought’ possibilities for us as human beings who care for each other” (p. 47).

Conclusions

The profound gap in socioeconomic indicators such as education attainment, income earnings, and epidemiologic morbidity/mortality data reveal a picture that demands exploration of the complex contributing factors. What is most impressive is the extraordinary room for improvement that might be envisioned not only for this specific

community, but for others in the region. Although the findings derived in one setting may not directly apply to all similar settings, findings may be adapted to fit other rural/remote indigenous communities since the processes of marginalization and oppression are globally prevalent.

Exploring the spatial regions that exist between *whitestream* and Indigenous is what Grande (2008) termed the “space of engagement,” and she defined this as the “liminal and intellectual borderlands where indigenous and nonindigenous scholars encounter one another, working to remember, redefine and reverse the devastation of the original colonialist encounter” (p. 234). Perhaps it is the ability to create functional partnerships, collaborating across the Indigenous – colonizer hyphen, which will prove to be of the greatest significance.

CHAPTER 2

To fully appreciate the purpose of this critical ethnography, review of the current literature regarding healthcare delivery as it relates to indigenous people and health disparity indicators is important. Themes are divided into five key components and echo the aims of the study:

- 1) Cultural diversity and health disparities,
- 2) Indigenous views on healthcare,
- 3) Cultural sensitivity of providers and investigators,
- 4) Integration of traditional spiritual and healing practices within the Western healthcare system, and
- 5) Community-based participatory research (CBPR) and coalition building.

The literature search revealed many international studies, reviews and theories covering culture, provision of medical and mental health care, development of culturally appropriate education and delivery formats, and devising appropriate CBPR, yet few were directed specifically towards uncovering the views of indigenous people concerning their healthcare.

Key definitions for the concepts which consistently arise are provided prior to a thorough investigation of the extant literature. These concepts include: 1) Culture and cultural safety, 2) Oppression and marginalization, 3) Hegemony and power differentials, and 4) Rural/remote outpost.

Conceptual Definitions

Particularly when working across multiple worldviews, it is essential to frame key concepts in such a way that there is no misinterpretation of purpose or findings.

Consensus may not always be attainable because many terms hold varied significance, but importantly, these definitions provide a platform from which further discussion and engagement can begin.

Culture and cultural safety.

The evolving face of politics, globalization, transnational immigration, and pan-ethnicity challenge a simple definition of culture (Lee, Rosenfeld, Mendenhall, Rivers, & Tynes, 2004). Any individual concurrently holds multiple cultural identities based on engagement in the world around him or her (Sen, 2001). Indeed Kleiman (2006) viewed culture as self-interpretation of one's life-world in the setting of lived experience, which is dynamic in nature. For the purposes of this study, the following definition will be followed (Lottis, 2008, p. 35):

The shared behaviors and mindset learned and embodied through any combination of ethnic, social, political, spiritual, philosophic, health, geographic and/or institutional *norms*. Highly fluid and multiplicitous, elements will shift for individuals and communities as roles and circumstances change.

In the face of diverse cultures each individual may embody, the ability to interact in safety, regardless of whether one's culture is considered mainstream cannot be understated. The Nursing Council of New Zealand (NCNZ, 2005) developed the concept of *cultural safety* from early work by Irihapeti Ramsden, and in an attempt to highlight this process for nurses, defined it as "The effective nursing practice of a person or family

from another culture, [that] is determined by that person or family” (p. 4). This document then defined *unsafe cultural practice* as “any action which diminishes, demeans or disempowers the cultural identity and wellbeing of an individual” (p. 4).

Marginalization and oppression.

Merriam-Webster (2009) defined marginalization as “To relegate to an unimportant or powerless position within a society or group.” Marginalization is then the first step towards oppression which is the “unjust or excessive exercise of power” (Merriam-Webster). While colonialism’s overt marginalization and oppression is a thing of the past, the post-colonial era continues to produce insidious messages that arguably are as damaging as overt oppression.

Mainstream or *whitestream* determines acceptable color, ethnicity, sexuality, health, economic, or educational success, and those who do not fit are pushed to the periphery, effectively silenced. Tashiro (2005) discussed the “invisibility of whiteness” (p. 206) and the prominent, albeit artificial, claim that race exists primarily for those who are non-White. This ideology of Whiteness perpetuates an invisible circle of power, creating a dynamic of those who belong and those who are relegated to the margins. It is this marginalization that Vasas (2005) believed creates vulnerable populations. Freire (1970/2000) considered this to be a cultural invasion in that “Invaders penetrate the cultural context of another group, in disrespect of the latter’s potentialities; they impose their own view of the world upon those they invade and inhibit the creativity of the invaded by curbing their expression” (p. 152).

This somewhat intangible concept of oppression can be challenging to identify and is what Harvey (1999) defined as “civilized oppression.” Insidiously obscured in the dominant social discourse, interactions diminish status and control actions with those who have little recourse due to uneven power differentials. Harvey stated that “Individual victims of oppression are typically recipients of cumulative harms, with a compounding significance not grasped by the more fortunate” (p. 38). He goes on to discuss systematic blocking by institutional ‘refusal to engage’ which leads to “disempowerment of the most vulnerable” (p. 128). Walters and Simoni (2009) furthered this concept of ‘othering’ by a process of exclusion from minority research in academia, challenging egalitarian participation, and rendering the oppressed further invisible.

Hegemony and power differentials.

Any discussion of oppression must include the concept of hegemony in the context of exploring the narrative experiences of Others. Elliott (2005) stated, “‘The hegemonic’ is understood as those ideas, power differentials, and structural arrangements that are so securely embedded in the social fabric that they literally ‘go without saying’” (p. 146). In the case of Western healthcare delivery, which has traditionally been paternalistic in nature with a hierarchal power differential (Cody, 2003), these attitudes toward power and control must be examined. In the case of indigenous people, colonization produced such a damaging power dynamic that perceptions of ‘power-over’ imbalances will impact how individuals communicate, relate, and trust — including the healthcare system (McCaslin & Breton, 2008).

Vasas (2005) discussed the use of 'horizontal power' used by those who experience marginalization, as being not only a form of opposition to mainstream, but an approach that values commonalities and relationships. This horizontal power dynamic, if utilized, proves most powerful within the liminal intersections of society. Vasas stated, "Understanding and valuing horizontal power means that we deconstruct the powerful/powerless binary of the Center/Other, and instead find potential in a type of power that often remains hidden" (p. 198). For healthcare delivery, the provider's use of power is a choice which must become reflexive and conscious.

Rural/remote outpost.

There are numerous definitions by various government agencies for rural communities based on population and distance from urban centers; however these seldom capture the contextual nature and demands of rural healthcare delivery. For the purposes of this study, the following definition of rural will be used: "The isolation of an individual or community geographically and politically, with limited access to resources including health care, with personal hardship through time/travel/finances; a framework of hardiness/independence which acknowledges importance of community and family for survival" (Lottis, 2008, p. 34).

Frontier or remote outpost communities face even greater geographic isolation, compounding political and socioeconomic disadvantage. Tarlier, Browne, & Johnson (2007) stated Canadian remote communities are largely populated by aboriginal

residents, who are “more vulnerable to experiencing fragmented care because of the health and social inequities that exert a profound effect on health status” (p. 128).

Review of the Literature

While a plethora of articles and research relating to health disparities and working across cultural boundaries exists, finding studies that directly relate to the unique needs of indigenous people are much less plentiful. However, research and cross-cultural theoretical frameworks for other marginalized populations do provide insight into areas for future exploration and consideration. Thus the literature review will not be confined simply to indigenous-people groups, but rather explore the following themes: 1) Cultural diversity and health disparities, 2) Indigenous views on healthcare, 3) Cultural sensitivity of providers, 4) Integration of traditional spiritual and healing practices within the Western healthcare system, and 5) Community-based participatory research (CBPR) and coalition building.

Cultural diversity and health disparities.

In the last decade or more there has been ever-growing attention to the health disparities experienced by minority and ethnic populations, and the dire importance of attending to these gaps, not only to improve quality of life and decrease suffering, but from an economic and justice-based requisite. Poignantly notable in a literature review on discrimination and health disparities by Williams and Mohammed (2009), was that out of 115 articles between 2005 and 2007, only three examined the needs of indigenous populations. They also reported mental health status as the most frequently documented

health outcome of discrimination with an inverse relationship throughout the extensive literature review.

Thomas, Benjamin, Almirio, and Lathan (2006) discussed historical policy implications in health disparities along with current policy decisions. They noted that significant gaps in morbidity/mortality exist across all minorities despite decades of focus, and indeed, noted institutional willingness to set separate (lower) objectives for minorities than others, which essentially condones these gaps.

In 2005 the Society for Public Health Education (SOPHE) convened a summit that would examine research agendas across transdisciplinary fields for disparities beyond race/ethnicity to include age, gender, disabilities, economic inequality, and other social factors affecting health. Woodhouse (2006), Green and Quinn (2006), along with Thomas, Benjamin, Almirio, and Lathan (2006) discussed and analyzed documents from the SOPHE gathering, and summarized as follows:

- 1) the importance of adequate dissemination of research and social justice activities,
- 2) the importance of societal responsibility in recognition of oppressive acts, including the contribution of current concepts that subtly maintain power hierarchies by creating negative comparisons,
- 3) the importance of translational research as a process of empowerment rather than using the disempowering deficit approach,

- 4) use of critical CBPR, and
- 5) mentoring of new researchers in health disparities.

These authors encouraged movement from simple policy ‘talk’ to that of ‘action’ methodologies which develop social justice and equity towards the elimination of health disparities.

Andrulis (2003) identified five areas that pertain to major causes of disparities and influence outcomes in disease management: biological/genetic, access, differences in quality, perceptions and realities, and barriers to communication. Recommendations focused on improving the patient/provider relationship and communication strategies, adaptation of clinic protocols, involvement of community groups to strengthen ties and assist in education, and recognition of complementary or non-allopathic treatment modalities. He also placed responsibility on government and administrative entities for leadership and guidance to practitioners in addressing disparities.

Loewenson (2007) reviewed international research, policies and implications of HIV/AIDS and noted that infection rates continue to increase in populations made vulnerable by socioeconomic and political disadvantage, and that this vulnerability translates into increased susceptibility and stigmatization. Findings revealed that communities that have positive social capital, and work toward empowering members played a positive role in reducing infection rates.

Each of these articles amplified the significant health disparities in populations marginalized by race/ethnicity, socioeconomics, or politics. Each stressed the importance

of involving affected communities in the change process, as well as the responsibility that mainstream society must accept for the oppression and marginalization of these populations. In research, as in healthcare, this requires a deep sensitivity to the cultural contexts in which we work.

Indigenous views on healthcare.

There is extremely limited data to support how indigenous people view their healthcare as received. Many of the healthcare investigations focused on the providers, and interviews with indigenous care recipients were placed as one small segment of the study, if at all. Nonetheless, those studies that are available reveal an undercurrent of distrust and dissatisfaction. Closely linked to understanding views of healthcare, is to discover how these experiences impact presentation and engagement with the system at large.

Guadagnolo, Cina, Helbig, Molloy, Reiner, Cook, and Petereit (2009) noting the scarcity of research focused on Native American healthcare disparities, specifically examine the influence of ethnicity and cancer care. They collected data exploring trust and healthcare perceptions, considering these critical to the creation of appropriate interventions. The study was part of a CBPR, and surveyed both Native and non-Native patients attending a regional cancer institute. Findings revealed Native Americans exhibited a significantly higher medical mistrust and decreased satisfaction with care when adjusted for variables such as geographic distance, income, education, age, gender, and employment. Also of note in this study was the higher incidence of Native American

people presenting with stage III-IV disease in cancers that have screening tests available. One of their recommendations was the use of Native Americans to be trained as liaisons in the healthcare system.

Garrouette, Kunovich, Jacobsen, and Goldberg (2004) associated patient satisfaction among older Native Americans with level of ethnic identity, finding those with higher Native American ethnicity had lower satisfaction with healthcare providers' social skill and attentiveness. Limitations included a written survey tool which only dealt with the perceptions of a single visit. Low literacy of respondents in conjunction with provider awareness of ongoing research may have been confounding variables. A longitudinal, blinded study with simple surveys and interviews conducted by Native Americans may have strengthened these results.

A number of studies explored the perceptions of healthcare providers who work with indigenous people. Watson, Hodson, and Johnson (2002), as part of a larger project on the experiences of remote Australian Indigenous women who come to give birth in an urban hospital setting, examined the opinions of the primarily non-indigenous providers (18 non-indigenous, 1 indigenous). Findings included awareness that the hospital and birthing experience for most indigenous women caused anxiety, fear, and loneliness, and that the women had little preparation for the hospital experience or adequate postnatal education. Providers were somewhat contradictory in that they believed care was equal between indigenous and non-indigenous, yet also acknowledged that communication and cultural barriers impacted the care given. This study also noted the profound loneliness

and isolation indigenous women reported when receiving care in urban centers far away from their home communities and support systems.

Hunter (2002) discussed the paucity of mental health research and delivery for Australian indigenous people, noting the continued generational trauma post colonization and the ‘stolen generations’ where children were forcibly removed from their homes. Hunter expressed concerns regarding the tendency to medicalize social justice issues, thus shifting the *blame* to the oppressed, as well as the inability of the mental health system to deliver an equitable or culturally appropriate service.

Eley, Young, Hunter, Baker, Hunter, and Hannah (2007) surveyed mental health staff as well as Indigenous consumers. Results revealed that mental health services did not meet the needs of the Indigenous population, who had little knowledge about mental illness, and felt stigmatization at being labeled mentally ill. The majority believed that the only way to access care was through the police and being ‘locked up,’ and, many knew of friends or family who had ‘bad experiences’ in the mental health system — thus they identified fear and mistrust throughout the responses. The authors discussed findings revealing significant communication barriers, with failure to address the needs and fears of the Indigenous communities. Interestingly, 73% of mental health providers were unsure of whether the system was accessed by Indigenous consumers, but *thought* that most did obtain access, while 50% of Indigenous participants stated that they did not access the system. Recommendations were to increase culturally appropriate care through

mandatory training of providers and genuine partnerships that would include Indigenous members in the design and administration of mental health services.

While there are few studies that specifically attend to indigenous points of view, exploring perceptions of discrimination by other minority groups provides insight. In a comprehensive literature review of perceptions of discrimination and impact on health-care, Williams, Neighbors, and Jackson (2008) found an inverse correlation with perceived racial/ethnic discrimination and health. Although gaps remain in the literature, these authors contend that the effects of discrimination on health are underestimated because of the failure to accurately measure cumulative effects of stress based on acute and/or chronic discrimination as well as blocked opportunities or ‘nonevents.’ The multidimensional nature of discrimination creates difficulty in accurately measuring this concept and they recommended further research.

Facione and Facione (2007) explored the impact of perceived prejudice of women in receiving cancer screening or presenting for care of symptoms with the use of scales that differentiate the perception of prejudice with the experience of prejudice. They note that personal perceptions of prejudice were related to poorer outcomes on key preventative health behaviors, and 87.3% of the 838 women sampled believed healthcare delivery to be prejudiced in some way. Notable was that this study included only Black, Hispanic, and White women, although it did capture sexual orientation and nativity status (U.S. born or immigrant).

Other studies explored the level of satisfaction with healthcare across populations and found positive health outcomes were associated with increased satisfaction. Concomitantly satisfaction was linked directly to interpersonal connections, including provider honesty and respect, involvement in treatment plans, and adequate information (Alazari & Neal, 2003; Auerbach, Kiesler, Waratella, Rausch, Ward, & Ivatury, 2005; Britto, DeVellis, Hornung, DeFriese, Atherton, & Slap, 2004). The alternate side of this picture was explored by Taylor, Marcanantonio, Pagovich, Carbo, Bergmann, Davis et al. (2008) where the presence of any service quality deficiency during hospitalizations “more than doubled the odds of any adverse event, close call, or low risk error” (p. 224). They made recommendations that particular attention be placed on improved communication with patients, and attentiveness to concerns regarding service quality.

Cultural sensitivity of providers and investigators.

In Canada, Browne (2005) explored the social and professional discourses which influence nurses’ knowledge and assumptions of First Nations patients. Despite expression of the egalitarian ideals of nursing, dominant social stereotypes and cultural assumptions were voiced. Browne noted that during the time of this study, Canadian treaty talks were ongoing, stimulating greater political awareness of the ongoing aboriginal/governmental debate.

Tarlier, Browne, and Johnson (2007) examined the influence of geographic and social distancing on nursing care in remote First Nation communities. Findings included lack of cultural or professional preparation for nurses presenting to these remote

communities, despite an initial orientation. Nursing practice was significantly different than in an urban or even rural setting, and was confounded by the profound inequities of social and political marginalization that included extreme poverty; no running water; substandard, crowded housing; limited supplies; and expensive food choices. Tarlier et al. commented that one particular community received 70 different nurses over a two-year period, illustrating the extremely high turnover rate with virtually no continuity of care faced by many remote outpost sites. These aspects all lead toward social distancing where nurses seldom participated in community life — creating a bidirectional ‘othering’ that fostered further disengagement and disassociation by nurses. This dynamic was reflected in the nursing care, and led to a focus on ‘acute’ scenarios rather than a more comprehensive community health approach. Recommendations were to research and develop appropriate formal educational programs for providers working in remote areas, as well as to critically examine the policies and behaviors that impact social determinants of aboriginal healthcare delivery. Replication of these findings in other communities is important, as is exploration of communities where efficient healthcare delivery and positive provider relationships exist, in an attempt to discover positive contributing factors.

Garrett and Pichette (2000) elaborate the challenges faced by indigenous people as they have been forced to learn to walk in two worlds. These authors devised a simple tool to assist practitioners to determine the level of acculturation and understand the vastly different worldviews that many indigenous people must balance. While the level of acculturation is an important element in appropriate communication and health education,

the context in which surveys are administered, as well as the identity of the person performing the assessment, may limit reliability of the instrument.

Bringing cultural sensitivity and awareness to any interaction is essential. Clear (2008), in her discussion of cultural safety, stated that cultural generalizations and descriptions of beliefs or practices is undesirable as this leads to simplistic assumptions and overt generalizations. She strongly contends that this is the difference between transcultural nursing and cultural safety, which focuses on the unique needs of each individual and community. Browne, Varcoe, Smye, Reimer-Kirkham, Lynam, and Wong (2009), place cultural safety into a criticalist framework, creating a “social justice curriculum for practice” to implement at both individual and institutional levels (p. 167).

Lowe and Struthers (2001) report Native-American-conducted focus groups from which a model was created highlighting essential dimensions of nursing in Native American culture: “(a) caring, (b) traditions, (c) respect, (d) connection, (e) holism, (f) trust, and (g) spirituality” (p. 280). This framework is in keeping with the concept of cultural safety, requiring participants to explore dimensions of a relationship potentially outside of established norms or assumptions.

Interestingly, while the study by Garrouette, Kunovich, Jacobsen, and Goldberg (2004), revealed an inverse relationship between ethnic identity and satisfaction with care, Wills, Mury, Brody, Gibbon, Gerrard, Walker, and AINETTE (2007) conducted a path analysis examining the relationship between ethnic pride and self-control to risk and protective factors. Results revealed that ethnic esteem was a prominent protective factor

in rural African American youth, with a direct effect to resistance efficacy. Conversely, negative self-concept was linked to both substance use and sexual behavior. Results suggested the importance of ethnic identity as a source of esteem in prevention programs, as well as effective education in confronting the stress of racial discrimination.

Halabi (2005) wrote of the challenges in completing studies with refugee populations who have little understanding of research, may have low literacy rates or be illiterate, and be mistrustful of researchers. She stated that quantitative approaches are inappropriate in these populations due to the literacy requirements and lack of culturally valid survey tools. However, qualitative studies allow participants to be heard and provide a mechanism for relationship building, and thus a potential for further education and interventions. Above all, for Palestinian refugees, it was the relationship to the interviewer and the demonstration of culturally appropriate respect for participants that gained access and high quality data.

The ethics of working within multicultural environments as well as confronting social injustice are prominent throughout the literature. Harper (2006) offers a concept analysis on 'ethical multiculturalism' and defined this as "the use of moral reasoning to apply ethical principles of beneficence and respect for persons and communities in a culturally competent manner to research in various societies or cultures" (p. 110). Harper considers whether cultural competence is truly attainable, as well as the philosophic differences between universal justice versus postmodern relativism. One could argue that the concept of ethical multiculturalism without an attendant component of social justice

still promotes a hierarchal structure, with the researcher as the ‘expert.’ However, if ‘ethical multiculturalism’ is contextually grounded in cultural safety, where it is the participant/recipient who sets the standards, this has the potential to be a powerful format.

Integration of traditional spiritual and healing practices.

The effects of colonialism have had longstanding repercussions in the use of traditional spiritual and healing practices for indigenous peoples. While some of the old wisdom has been lost, more is being retained within the close confines of the community. The healthcare provider must explore traditional healing modalities such as the use of herbs, healing practices, and spirituality, as this information is rarely volunteered. While the interactions between Western pharmaceuticals and herbal preparations is essential to be aware of, respect for a patient’s connection to, and involvement with traditional healing practices promotes a relationship of trust.

Mulaudzi and Makhubela-Nkondo (2006) undertook a grounded theory exploration of indigenous healer’s beliefs concerning sexually transmitted diseases in Africa. They discovered that many indigenous individuals sought concurrent treatment from a hospital/clinic and a traditional healer, yet were ashamed to admit this to the hospital/clinic providers. Many people believed that, while Western medicine might treat the symptoms, it was the traditional healing/cleansing which solved the core problem. Thus, lack of knowledge concerning local customs and traditions may deeply impact care given.

These findings were echoed by Struthers and Eschiti (2004), who conducted a qualitative exploration of indigenous people with a cancer diagnosis who used traditional healing. These individuals integrated Western, traditional healing, and other alternative healing methods for a holistic and balanced approach. As this study illustrated, culture and beliefs, interpretations around the meaning of illness, and life all impact approaches to illness.

Community-based participatory action research.

Prevalent throughout the literature on cultural diversity and racial/ethnic health disparities is the importance of building trusting relationships, shifting paternalistic power differentials, and empowering communities toward self-regulation. Nowhere is this more powerfully evident than through community-based participatory research. The following articles offer a sampling of strategies of CBPR consortium and coalition building, beginning with educational programs, as these should be demonstrating leadership in collaborative strategies with minority populations.

Increasing numbers of academic institutions are documenting attempts to bridge the gap by including deep collaboration with indigenous community members, who participate in the development and teaching of the curriculum for specific courses. While all report positive outcomes and experiences for those involved, coursework is not mandatory and, participation by non-indigenous in learning effective methods of relationship-building appeared minimal, leaving the onus once again on the oppressed to

correct the discrepancy (Arnold, Appleby, & Heaton, 2008; Bindler, Allen, & Paul, 2004; Moss, Tibbetts, Henly, Dahlen, Patchell, & Struthers, 2005).

Hays (2002) reviewed the concept of James Cook University medical school, dedicated to serving the healthcare needs of the indigenous Australians of the region by indigenous representation in medical school management, staff selection, student selection, and curriculum content which imports a strong message of inclusion and change. As Hays stated (p. 287):

Perhaps the most important overall strategy is for the profession to regard Aboriginal and Torres Strait Islander people as important partners in improving health care and to role-model that approach. It is time to do less for, and more with, those who can make a difference.

Unfortunately this attitude is not consistent across academia, and much work remains not only to recruit indigenous healthcare workers, but to retain indigenous researchers. Walters and Simoni (2009) discussed impediments to American Indian/Alaska Native (AIAN) scholars who work in HIV and mental health fields, such as oppressive and unyielding educational systems, marginalization of research interests and ongoing discrimination. Concomitantly, these researchers were subjected to tribal mistrust because of previous scientific abuses, language and cultural barriers/differences, and a deficit of culturally grounded methodologies. Recommendations included research partners in the academe who embrace indigenous ways of knowing, building collaborative community partnerships between universities and tribes, and strong mentoring programs for new scholars.

The literature also revealed increasing numbers of community-based participatory researchers in practice settings as well. Holkup, Tripp-Reimer, Salois, and Weinert (2004) defined CBPR characteristics in their documentation of a community-based intervention against elder abuse in a Native American community (p. 163-164):

- a) recognizing the community as a unit of identity,
- b) building on the strengths and resources of the community,
- c) promoting co-learning among research partners,
- d) achieving a balance between research and action that mutually benefits both science and the community,
- e) emphasizing the relevance of community-defined problems,
- f) employing a cyclical and iterative process to develop and maintain community-research partnerships,
- g) disseminating knowledge gained from the CBPR project to and by all involved partners, and
- h) requiring long-term commitment on the part of all partners.

Ochocka, Janzen, and Nelson (2002) document a participatory action research program between mental health researchers and consumers/survivors in order to discover needed services and supports. The shared knowledge and power from this approach was founded by values of “consumer/survivor empowerment, supportive relationships, learning as an ongoing process, and social justice” (p. 379). This 30-month project provided an empowering learning opportunity for all team members, and offered new insights for the professional researchers in terms of shifting power differentials away from the traditional hierarchy.

Crawford and Brown (2002), through a series of focus groups with rural mental health providers and service users, identified areas of perceived stigmatization and its subsequent impact. These providers developed relationships that empowered clients to

identify, then jointly combat and prevent sources of stigmatization within the client's community setting, and maintain social networks. Additionally, providers were sensitive in acknowledgement of the institutional stigmatization that frequently occurs and consequently were able to gain trust.

Holkup, Tripp-Reimer, Salois, and Weinert (2004) offered excellent solutions to ethical issues such as confidentiality when community members are also research partners, ensuring communities not be cast in a negative light, and most importantly, ownership of intellectual property. These included clear discussions with all team members regarding the importance of confidentiality, and the addition of a 'Memorandum of Understanding' that essentially contracted that any article or presentation would be reviewed and accepted by all team members for assurance of integrity to the data and respect for the community.

Partnerships of this nature demand an evolving flexibility and action plan based on the concerns of participants. Schinke, Hanrahan, Eys, et al., (2008) described the transformational process of entering a community in order to uncover challenges to elite Aboriginal athletes. Yet as the project began, the community expressed different needs and a desire to be involved. This article documents the journey over greater than two years, where a transition occurred from a traditional research of aboriginal elite athletes into a CBPR, based on the community concern regarding declining physical activity and sports involvement by youth as they entered secondary school.

Consortiums and coalitions are other important ways to implement research protocols which impact communities. Mizrahi and Rosenthal (2001), as part of a large mixed methods study that examined coalition dynamics, operations, and outcomes, reviewed leaders' definitions and evaluations of coalition success, including leadership styles, strategies, struggles, and solutions. Findings led to creation of a conceptual framework for successful coalition building. The framework included:

- a) Conditions: political, economic, and community conditions must be conducive for development of a coalition,
- b) Commitment: a core group of people representative of different organizations, committed to the coalition concept and a common goal,
- c) Contributions: Ability to obtain required contributions — ideology, power and resources, and
- d) Competence: in moving toward a social change goal, maintenance of coalition leadership and membership base.

Andersen, Belcourt, and Langwell (2005) reported on the creation and progress of the Montana-Wyoming Tribal Leadership Council (TLC) with the specific goal of reducing the significant health disparities for the regional tribes. This consortium now includes multiple collaborators with the common goals of implementing multiple pilot research studies dealing with the highest community concerns, such as substance use/abuse, suicide, healthcare satisfaction survey, and seatbelt use, community outreach

and information dissemination, mentoring, shared resource data base, and establishment of a center for fetal alcohol syndrome.

Chino and DeBruyn (2006) offered a commentary on indigenous people creating and maintaining control of programs for indigenous people. The authors shared a model including elements of CBPR and capacity-building, but modeled specifically for indigenous contexts. The model, Community Involvement to Renew Commitment, Leadership, and Effectiveness (CIRCLE) is a cyclical, four-step process of: (1) Building relationships, (2) Building skills, (3) Working together, and (4) Promoting commitment. The authors spoke of the importance of collaborations with non-indigenous scholars in such a way that each can create positive outcomes with unique strengths and skills in a meaningful framework.

Conclusions

Consistent across the literature on culture and disparities was the agreement on widespread injustice for marginalized populations on the part of healthcare providers and systems, with prevalent cultural stereotyping and racial discrimination. Findings revealed increased level of ethnic identity related to decreased satisfaction with service, and this impacted utilization of healthcare. Native American individuals were more likely to present to care with late stage cancer and other chronic diseases that screening was available for.

Gaps in the knowledge continue regarding the perceptions of marginalized populations, and how these impact presentation to healthcare. These findings call for a

multicultural focus on increasing satisfaction with care, with increased use of screening and preventative services as one possible measurable outcome.

Other means of measuring outcomes are satisfaction surveys, and several studies with indigenous populations did use a survey format. However, even if determined valid and reliable, these must still be used with caution due to literacy levels and the contextual nature of responses. At the very least, any studies with survey tools should be designed by or with the community involved, then blinded, applied longitudinally and/or verified through the use of confirming interviews with appropriately trained personnel, preferably from within the local indigenous community.

The requirement for further education, discussion, and examination of mainstream social discourses, as well as the mechanisms that inform interactions with others was woven consistently within study recommendations. Underlying themes referred to the importance of research that promotes indigenous needs and interests, reverses the traditional power structure, and gives ownership of the results to the community so as to create empowered movement toward social change. Improvement in outcomes will not occur unless programs are developed based on the voices of, and in partnership with, the indigenous.

Many of the articles and studies reviewed spoke to the dearth of high-quality studies done with indigenous populations, or the desperate need for improved education and collaboration — yet few directly confronted the lack of mandatory and/or breadth of culturally-appropriate education either for students, faculty, providers, or administrators.

The innovative institutions that offered educational programs, taught in part by indigenous elders as part of the curriculum, show promise for leading the way in multicultural studies. However, participation appeared limited, and options that appeal to the mainstream student body, if not a mandatory track for issues around cultural sensitivity, is an important element in future curriculum development for all educational institutions.

While not always purposeful, instances were shown where the severe disparities in social determinants of health, in conjunction with lack of cultural or professional preparation were overwhelming, placing barriers and causing social distancing. A shift towards a framework of cultural safety must be included in healthcare that is firmly situated in social justice.

Kincheloe and McLaren (2003) stated "... power is a basic constituent of human existence that works to shape the oppressive and productive nature of the human tradition" (p. 439). Mainstream researchers, scholars, and healthcare providers must reflexively determine their approaches to power and ask whether these serve to *empower* and *engage*. Part of this engagement is to listen and understand the needs of the patient/community, as members may have different values and perceptions of priorities. Development of CBPR and collaborative coalitions are frameworks for transformation. Vision and creativity are necessary if any impact will be made on the health disparities experienced by minority populations. As Fine, Tuck, and Zeller-Berkman (2008) stated, participatory action research is, at once, "Social movement, social science, and a radical challenge to the traditions of science" (p. 160).

CHAPTER 3

The Purpose, Questions, and Specific Aims

The purpose of this study was to explore experiences with, and views of, the healthcare system among remotely situated First Nations people of coastal British Columbia (BC), to shed light on elements considered crucial to healthcare delivery. From a transformative/egalitarian lens, a critical ethnographic study must be conducted through partnership with the communities of interest. True partnership is defined by the ability to share worldviews productively, including through scholarship.

Chapter three honors this process, both culturally and aesthetically, through the holistic description of methods in conjunction with traditional research language. Geertz (2000) described this effort as an attempt to “gain a working familiarity with the frames of meaning within which they [participants] enact their lives” (p. 16). Lincoln (2002) proposed that all research, and especially ethnographic inquiry situated inside communities is *communitarian* in nature, aiming not only to discover, explore, inform, and interpret for purposes of change, but also to transform academic exercises to community projects on behalf of people. In this way, I considered the use of metaphor between phases of the research process and the cyclic activities that maintain life, sustenance, and traditions in these indigenous communities to be an important frame of the research.

Additionally, inviting several community members to copartner in this investigation was more intuitive as the language carried meaning not only for the formal academic enterprise but also for the local ways of interpreting process and applying actions to

healthy outcomes (e.g., surviving, nourishing community, sustaining the traditions). Therefore, the following links were made between research activities and the comparable seasonal tasks in the investigation: Research Design compared to *Carving*; Setting and Sample to *Drawing the Circle*; Data Collection to *Gathering*; Data Management and Data Analysis to *Hunting and Fishing*; and Ethics/Rigor to *Preserving*.

After presentation of the research questions and specific aims, *Carving* the Research Design refines theoretic and methodological foundations. *Drawing the Circle* recognizes the importance of relationships and will describe the Setting, Participant Selection and requirements, Community Partnerships, Sample Size, and gifts given as honorarium for involvement. *Gathering* and *Hunting/Fishing* describe the Data Collection, Management, and Analysis components. Finally, *Preserving* details the ethics of the study, without which the hard work of hunting and gathering, collection, and analysis would be rendered moot and without lasting significance.

Specific Aims

To answer these questions, the Specific Aims of the study are:

- 1) to describe how First Nation people view their healthcare,
- 2) to explore how past experiences and views of healthcare influence presentation and care utilization,
- 3) to compare First Nations members' views of care received in remote outpost clinics versus care received in distant urban-center settings,

- 4) to explore the impact of a healthcare provider's cultural awareness on the level of healthcare system engagement by First Nation members, and
- 5) to explore the degree to which First Nation individuals integrate traditional healing with the Western healthcare system, and the prevalence of discussion and reaction to such integration with the healthcare provider.

Carving: The Research Design

Through a First Nations lens, for the carver many years of study and training precede the first piece of art. Whether ivory, stone, or wood, it is the nature of the substance which 'speaks' itself into existence – the vision that comes to the artist and is then carved into a representation of living essence. The carvings of the Northwest coastal people express the historic collective from which clan stories arise. In much the same way, the well-crafted Research Design organically develops based on theories and experiences best suited to the aims and purposes of the conceptualized study, co-generated between the participants and the researcher.

In a setting with documented indigenous health disparities despite decades of multicultural awareness permeating the healthcare system, two priorities were considered essential. The first was to explore and chronicle the perceptions of the individuals directly concerned, and the second, to engage these communities in such a way that a vision for improvement can be manifested from within. To honor indigenous voices and help awaken dialogue, the most appropriate methodology to accomplish these tasks was that of narrative inquiry embedded within critical ethnography, attending to the hegemony of

power and resulting social injustice that has long characterized the participants' experience (Kincheloe & McLaren, 2003; Madison, 2005).

Narrative inquiry.

Narrative inquiry provided a vehicle for organizing sequences of events into a meaningful whole, and the recognition that these events were intrinsically linked to past, present, and future (Dunbar, 2008; Elliott, 2005; Garro & Mattingly, 2000). For marginalized communities that have suffered historical as well as present-day oppression, narrative inquiry explored not only current experience but the oral tradition of ancestral stories which inform responses to society at large. Understanding emerged from within this history, not aside from it.

Interviews obtained while participating in daily community life were an important element of anchoring perceptions within the situated experience. Elliott states that narrative can “give a voice to the most marginalized groups within society” (p. 144), and that the act of listening on the part of the researcher shifts the power differential in a positive way for the narrator. It is the meaning-making that each participant builds as the story is told — not the specific facts, but rather how those events shaped their attitudes about self and others with which this study is concerned.

While the primary mode of data collection was individual interviews, the first step was to establish trust and rapport by simply participating in community events, renewing old friendships, and being consistently present to ‘talk story.’ The act of engagement and communion in the lives of others creates relationships, and allows a non-threatening

entrée in which to build increased levels of trust. As trust and curiosity grew, open-ended interviews were completed (see Appendix C), where individuals were encouraged to speak the truth of their experiences. The flexibility of narrative interviews allowed participants to control the process through provision of as much or as little detail as comfortable, when and where to hold the interview, whether to follow up with additional details in the stories, and whom to include for support as desired.

Ethnography.

Individual perceptions are a key component in narrative inquiry, and these individual experiences combine to shed light on the greater social structure. Madison (2005) stated “the interview is a window to individual subjectivity and collective belonging: *I am because we are and we are because I am*” (author’s emphasis, p. 26). Thus narrative was carried out from within the greater context of ethnography which provided the mechanism for me to witness and participate in day-to-day activities and relationships, forging a link with how these influenced attitudes toward life events. It was the society as a whole that was of interest and multiple sources generated the rich insights and data, such as observations from daily chores, dances, a wedding, funerals, a graduation potlatch, photographs, and carvings. Visual representation through art and photos provided an avenue of expression, delving below the words, connecting the stories at a visceral, pre-verbal level. Aesthetic components may offer a bridge between Others, and speak in places where words alone may be insufficient. In this manner relationships of trust were initiated that formed the foundation of forthcoming interviews and deeper understanding from the participant perspective.

Critical/transformational paradigm.

Post-colonial research, particularly in a remote indigenous community such as this, ethically required a level of engagement beyond that of traditional ethnography, which aims to observe and describe what a particular group is doing. For this reason critical ethnography was chosen, as it acknowledges the place of each individual within the collective, and urges reclamation and empowerment. Questions and responses were constructed from the contexts of culture, history, human experience, patterns of migration and marginalization, economics, politics, and healthcare practices. Partnership with community members in this endeavor was the only way to assure a culturally responsive research practice, with acceptable research being defined and configured from within (Denzin and Lincoln, 2008). Critical ethnography not only promotes collaboration, but provides a vision and potential power base from which communities might claim control, and is thus transformative in nature. Madison (2005) stated that “subjects themselves benefit from this proclamation through the creation of space that gives evidence [that] ... ‘I am in the world under particular conditions that are constructed and thereby open to greater possibility.’” (p. 173). Collaboration with this remote First Nations band worked to promote a deep level of understanding between those involved, creating a doorway through which new relationships and processes can be imagined.

Drawing the Circle: The Land and The People

Understanding the complexities of isolated living, and the hardiness of those who live in these remote regions provides a greater understanding of the unique challenges to healthcare delivery in remote outposts.

The land: setting.



Figure 8. Heading up one of the many NW inlets en route to community. Lottis, 2010

Indigenous traditions living within a circular philosophy are shaped by relationships, whether human, plant, animal, elements, land, and/or sea. Fixico (2003) stated that “a ‘circular’ approach toward life is inherent in Indian cultures since time immemorial. The native world is one of cycles, and observing the cycles provides an order to life and community” (p. 42). Meyer (2008) defined the land as “the everything to our sense of love, joy, and nourishment. Land is our mother” (p. 219). The naturalist Aldo Leopold (1987) described the extension of relational ethics and attachment to the land like this: “In short, a land ethic changes the role of *Homo sapiens* from conqueror of the land-community to plain member and citizen of it. It implies respect for his fellow-members, and also respect for the community as such” (p. 204). This relationship is foundational and determines the flow of community life within the seasons.

The land, climate, and ecology significantly impact daily life, mobility, and by extension, human health, and thus it is useful to explain the particular details of the setting for these participants. Along the rugged central coast of British Columbia (BC), seasons are dramatic and the cycles distinct. Appendix A provides a map of BC. Fall and winter are punctuated by harsh storms, dense fog, freezing rain, and snow. This is the time for family — games and stories are shared. Spring and summer bring temperate days, wild flowers, berries and fruits, fish runs, and collection of herring roe and seaweed. Gathering and preserving the harvest are intensive events, and they build a sense of coherence in these communities. This is a land of unsurpassed beauty, and it is a gift to experience its majesty.



Figure 9. Demonstrates the beauty of the numerous islands along the coast, en route to the First Nation community. Lottis, 2010.

Within a land of countless inlets, islands, and thick forests where cedar trees still span over 40 feet across, bears, wolves, and eagles coexist with the coastal people. The

only means of transportation in and out of the village is by boat or seaplane. The mountainous terrain and treacherous currents of the labyrinthine waterways require a deep knowledge and abiding respect for nature and the challenge of survival. Geographic isolation is a fact of life.

The people: participant selection and sample size.

With longstanding family connections to several aboriginal Canadian communities, I always look forward to the opportunity to reconnect. Recently, several band members spoke of concerns about the efficacy of local healthcare and recognition that these issues of disparity were similar not only along the coast, but common to Indigenous health across North America. The results of these meetings and the ensuing stories specific to this village resulted in unofficial invitations, as it was felt that opportunities to share their experiences may shed light on specific local issues. Band council was contacted, and official permission was requested and received from the chief to meet with community members.

With total band membership of just under 500 people participant selection was a delicate endeavor. Indeed participant selection in this setting was a misnomer, as it was the individuals themselves who selected the degree to which they chose to become involved with the study, if at all. A long history of uneven power differentials demanded that as a member of the *whitestream* I acknowledged my place as invited guest, and no direct approach was made at any time requesting volunteers for the study. Rather

community partners made introductions that allowed community members to initiate interaction as trust, interest, and curiosity in the project developed.

Introductions and explanations of the research purpose in lay terms were provided (see Appendix D) with the assistance of key community members who believed in the value of this research and who had committed to active involvement. Interviews were conducted only as participants expressed willingness to engage in a dialogue about previous healthcare experiences. My presence and involvement in daily activities over the course of five weeks provided ample opportunity to indicate interest in the project. The positive experience of telling one's story created a snowball effect and others also volunteered.

Each participant was 18 years of age or older, had some previous interaction with the healthcare system, as patient or family member, and was capable of giving verbal informed consent for him- or herself. While all community members spoke English, each was offered the choice of conducting the interview in their native language. While each made the choice to conduct the interviews in English, frequently native language words were interjected in descriptive efforts to fully describe the phenomena at hand. With the help of community partners and experts, these words were translated, either at a later time or during the interview itself.

Sample Size.

In qualitative research, sample size is not determined by a predetermined formula, but by saturation of the data. Bowen (2008) defined saturation as the time in which the

data set is complete “as indicated by data replication or redundancy” (p. 140). New participant interviews are added until saturation is achieved, and no new themes or conceptual categories emerge (Bowen; Crist & Tanner, 2003; Morse, Barrett, Mayan, Olson, & Spiers, 2002; Richards, 2005). Sufficiency of sample then indicates an adequate scope of data, appropriately represented by the participants and congruent with the purpose of the study and questions asked (Bowen; Richards). Creswell and Plano-Clark (2007) stated that the purpose of a narrative study is to provide in-depth, “detailed views of individuals and the specific contexts in which they hold these views” (p. 112). The authors went on to state that one to two interviews may be sufficient for narratives, or four to 10 for case studies.

In this project, where the questions were broad and allowed for divergent responses, and the group was relatively homogenous in terms of ethnic identity and experience of rural community living, saturation of the data occurred within 12 to 15 interviews. *Depth* of data was assured by returning to participants to verify accuracy, as well as expand and address possible gaps in analysis, while *breadth* was achieved by obtaining new participant interviews, seeking as wide an array of responses as possible and feasible. This demanded an iterative, flexible, and responsive relationship with the data, concurrent with collection, and was followed through memos and log trails in order to thoroughly document saturation and adequate scope.

Giftng.

In a traditional First Nation village, demonstration of respect is essential and one formally accepted way this is accomplished is through gifting. Thus, each participant was given a durable solar-powered flashlight or a southwest style blanket as honorarium for his or her time at the completion of the first interview, with an approximate value of \$20.00 U.S. each. Additionally, respect was given at the completion of the study, thanking those involved for the welcome received and participation offered, and to bring closure to the process, consistent with the traditions and customs of the community. Before leaving the communities, I gave gifts representative of the Southwest such as turquoise or fetish carvings to each chief and community research partner, again with an approximate value of \$20.00 U.S. for each gift.

Gathering: Data Collection

The harsh and unforgiving winters of the northern British Columbia coastline are tempered by the abundance of the other seasons. Cedar bark is harvested, and is the heart of both art such as carving, and utility, as baskets are woven to collect the wild berries and fruit. Gathering is communal and demands active involvement and participation. In this same way, collection of data required active involvement in day-to-day community work-life, celebrations, and dances, which began the process of building and renewing relationships.

While narrative interviews formed the bulk of the data collected, critical ethnography relies on multiple modes of information through means such as participant

observation of communal work and play activities. Ceremonial gatherings, relationships, and art all add substance to the final product and represent additional sources of data. Originating in Latin, data are “things given, information, etc., accessible in various ways” (Oxford, 2002, p. 348). Community partners were actively involved at each step in the process, providing cultural counsel and expertise. Field notes were consistently written in order to capture the wealth and texture of village life, as well as the flow and dates/timing for all research activities (Flick, 2006). However, I should clearly state that this project sought data that informed people’s experiences and relationships with healthcare, and did not explore or reveal traditional customs considered off-limits to the non-indigenous population.

Consent.

I verbally presented a simply worded script of study purpose and design, possible risks and benefits, and terms of involvement, including the right to withdraw at any point, and offered a written copy (see Appendix E). Those who participated in the tape-recorded interview were asked to sign a written consent, as a list was kept tying identity to interviews for purposes of subsequent verification. Anonymity was maintained for any who volunteered stories during the course of community events, and participation served as documentation of consent. All identifiers were removed from the transcripts, and pseudonyms were used for each informant. A single log, linking participant to pseudonym, was kept in my personal, password-protected computer. Three other anonymous interviews were accomplished with a physician, remote outpost registered nurse, and family counselors, all well-known in BC to be culturally-sensitive in working with First

Nation populations. Participation was acknowledged as consent to the digitally recorded interviews. All protected information will be retained until the dissertation is completed and defended. At that time, I will delete all digital data, and shred the hard copy of the log.

Collection.

Individual, minimally-structured, digitally voice-recorded interviews lasted approximately 60 to 90 minutes, and included the presence of community research partners, trusted elders or other family members as desired by participants. Appendix C lists the possible interview questions used. For individuals who agreed to the interview but were uncomfortable being taped, field notes and memos captured key themes and quotes. After transcription of the interviews, a second meeting with the participant was held in order to verify accuracy of intended meaning, as well as to explore any further comments or experiences considered pertinent. A verbal reminder of the right to withdraw from the study was again reviewed.

Additionally, as they were willing, I asked participants to visually represent their concepts of what health ‘looked like.’ These included photos and carvings depicting the process of health at whatever level was meaningful. No identifying photos of the communities or individuals were included in the study. Such visual data complement critical ethnography and capture a kind of sensory evidence and real-world meaning that may not emerge from verbal communication, yet represent a culturally-embedded, contextually

created vision. Visual data may also be interpreted as a site for knowledge construction and understanding (Pink, 2007; Sullivan, 2005; Wagner, 2007)

Privacy, confidentiality and security.

Privacy was a difficult thing to manage in a small village, thus locations for the interviews were determined by the participants. Having been in these communities previously, I visited many homes in order to re-establish old relationships, and expected that the home would provide the greatest confidentiality and comfort for storytelling. Other locations included boats, docks, village pathways, and porches. Interestingly, as interest and curiosity increased, private interviews became increasingly challenging as people consistently stopped by to add their own thoughts. The importance of confidentiality was expressed to community partners, who were asked to respect the right to privacy of each participant with whom they interacted.

Security of the data was accomplished in two ways. All digital material such as interview recordings, transcripts, and photographs were downloaded into my personal password-protected laptop computer to which no one else had access. Pseudonyms were used consistently throughout the data. Field notes, hardcopy photographs, and any other non-digital material were maintained in a locked trunk. Large art forms such as carvings were photographed and catalogued. Names or other identifiers were not attached to any data. Rather a computerized key was kept that linked pseudonyms to participants in order to accurately return for data verification. On return to the home office, all research data

was downloaded to a separate hard drive and will be kept in locked cabinet until completion of the dissertation defense.

Hunting/Fishing: Data Management and Analysis

Whether hunting for game such as deer or bear, or fishing for salmon, herring or oolichan, the hunter/fisher must understand the habits, cycles and patterns of what they hunt or seek. This is a learned process, taught by the elders, requiring patience and persistence, returning again and again to known sources; and so it is with Data Analysis — hunting for patterns in the data through constant reflection and comparison, guided by the mentorship of those with greater experience.

Data management.

Data consisted of participant-observer field notes, interviews, visual forms of art and photos, as well as previously gathered historical records, demographic and epidemiologic information and literature review. The qualitative software program NVivo-8, loaded on my personal, password-protected computer, assisted all management and analysis processes. Interviews and field notes were transcribed using the software; photographs and other art forms were also catalogued and entered. A back-up hard-drive was kept of all digital material and was kept, along with all non-digital forms of data in a locked trunk.

Data analysis.

Data was iteratively explored through immersion and crystallization. Janesick (2003) stated “crystallization recognizes the many facets of any given approach to the

social world as a fact of life” (p. 67), and is particularly fitting where worldviews between participants and researcher may be disparate. The holistic nature of walking the circle and determining that different perspectives are recorded, explored, and honored is imperative. This is a hermeneutic approach to both the community and the data, and from a criticalist framework cannot be accomplished in any other way. Kemmis and McTaggart (2003) believed that the “criterion of authenticity involves a dialectic ... seeing things intersubjectively, from one’s own point of view and from the point of view of others (from the inside and the outside)” (p. 347).

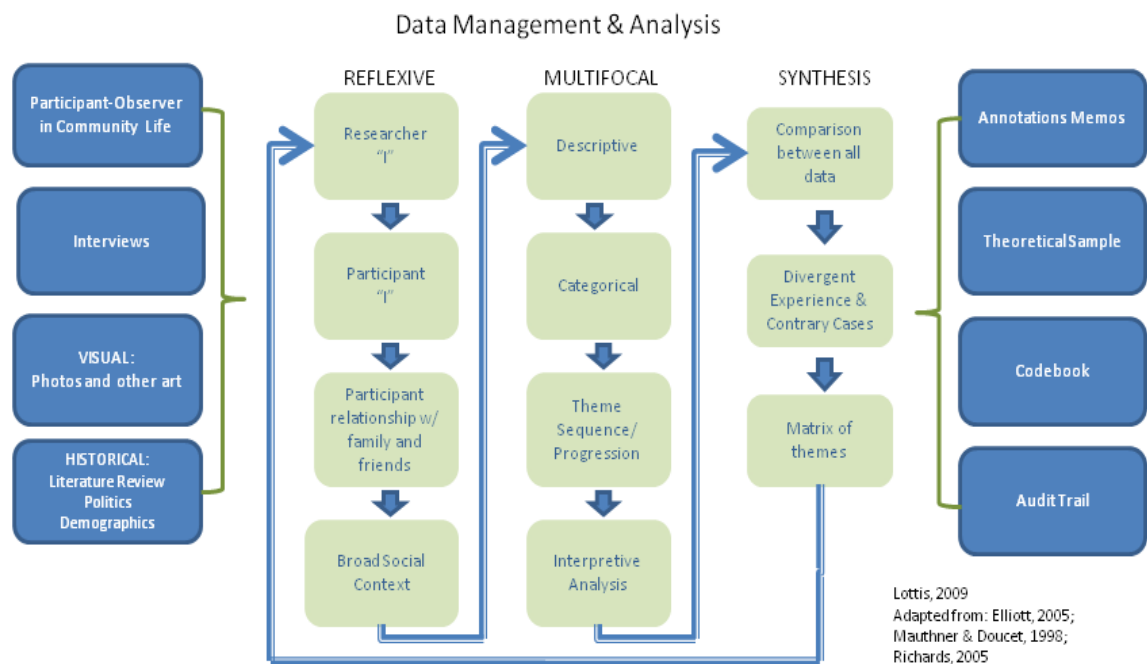


Figure 10. Data Management and Analysis Model. Lottis, 2009.

The process described in this chapter will be enhanced through visualization. While the phases are distinct, they are not necessarily linear, since rethinking, reflection, revisiting, and reinterpretation are part of the ethnographic process. I adapted and com-

bined earlier analytic schemes to create a diagram as depicted in Figure 10. The first phase is deeply reflexive, and must be noted before the data loses the emotional power of a fresh reading or hearing. This includes specific readings from the viewpoint of:

- 1) Reflexive/emotional:
 - a. researcher confronted with the data,
 - b. participant identity,
 - c. participant relationship with family and friends, and
 - d. the broader social context (Elliott, 2005; Mauthner & Doucet, 1998).
- 2) Subsequently, phase two brings more structured dimensions of perspective with readings for:
 - a. general descriptors including attributes and demographic
 - b. categories or topics that provide early organization, seldom requiring interpretation,
 - c. analytic coding, more abstract and interpretive in nature (Richards, 2005).
- 3) The third phase includes a synthesis through:
 - a. comparison between all data at each of the previous stages,
 - b. exploring and recording divergent experiences and contrary cases or observations, and
 - c. creation of a matrix of themes. Matrix analysis allows for graphic representation of themes, providing another means of recognizing

highly-populated versus seldom-used categories (Averill, 2000; Creswell & Plano- Clark, 2007; Richards).

Each of these phases was augmented by annotations and memos that linked segments, and tracked thoughts and analytic development; a codebook that revealed categorical and thematic emergence; as well as a careful audit trail that documented decisions made at each stage of analysis. Additionally, an ongoing memo justifying the process of theoretical sampling and determination of adequate scope and saturation was kept. This occurred through the development of general categories noted in data while transcribing and summarizing. Member checking with research partners occurred at key points throughout the process to assure culturally appropriate analytic consistency. Analysis of a qualitative ethnographic study is fluid and inductive, and always embedded within multiple contexts, i.e. the lives, relationships and surroundings of the community. As every society is in a state of flux, meanings and conclusions are not static, nor necessarily transferable (Kincheloe and McLaren, 2003). Yet the integrity of the study demanded that the findings were representative of the participant's experiences in this time and place.

Preserving: Ethics and Rigor

Survival of the coming harsh winters is based on community members all participating in preservation of the harvest through smoking, jerking, canning, drying, and rendering oil. After assuring the means of sustainability, the winter months, more than any other time, are concerned with the preservation of relationships — for feasts,

story-telling, and ceremony. For the research process, preservation of the relationships requires adherence to strict ethics and demonstration of trustworthiness.

Ethics.

The ethics of conducting qualitative research must include protecting the rights of those involved through such means as obtaining informed consent, protecting issues of privacy and confidentiality, reviewing risks and benefits, paying attention to potential researcher bias, and finally ensuring credibility, dependability, and transferability of the data (Lincoln & Guba, 1985). Mechanisms to protect the rights of participants included obtaining official permission from the band council to conduct the interviews after submitting a lay summary of the study purpose and methods. As this was an anonymous, observation- and interview-based study, considered to present minimal risk to participants, an expedited application to the Human Research Protection Committees (HRRC) through University of New Mexico was made and the “Investigator’s Protocol,” a synthesis of this chapter was included with the application, per HRRC guidelines.

The paramount duty of an ethical ethnographic study is to maintain the integrity of community and its members. For this reason, and to promote transparency of research, at the final gathering for closure, *all* community members were assured that interviews were reviewed with each participant for accuracy; privacy and confidentiality were, and will continue to be, respected; and a review of the purpose, methods, general summary of findings, and possible implications was offered. After successful defense of the dissertation, final copies will be sent to the band through the community research partners.

Informed consent.

Standard to all research is a mechanism for obtaining written informed consent. This again is to assure the protection of all participants and to inform them of the study's purpose and procedures. However, there are instances when signing a form, whether easily understood or not, may create unnecessary barriers to trust and rapport, especially in remote communities with little or no experience as research participants, or in cultures where the oral tradition of giving one's word is considered sufficient.

As no identifiers were included that linked the participants to the study, a waiver of the written consent form for those who volunteered stories that were not recorded was applied for through HRRC. However, for those who volunteered with recorded interviews, it was important to maintain a link for later verification. These individuals did sign an abbreviated consent form. Provision of a written script of consent was verbally presented to all participants, whether recorded or not (see Appendix E). The willingness itself to offer stories signified participant agreement for those individuals who were not recorded.

Privacy and confidentiality.

Privacy was safeguarded by allowing participants to choose time and place of interviews. Admittedly, confidentiality was more difficult to insure in a community where everyone knows if and when a member speaks to an outsider. However, the content of each interview was kept confidential and free of identifiers.

A number of participants were initially willing to reveal their identity. However, on verification, several participants requested reassurance of privacy due to accounts that included sensitive information regarding themselves and/or family members. Notably, in a small community where individuals are inter-connected by a complicated web of family ties and history, anonymity is not possible. Therefore, I expressed a strict desire to maintain privacy and confidentiality to all participants, recognizing that anonymity would be a challenge at best. Occasionally, I deleted or modified sensitive information by request of participants during secondary verification, in order to prevent harm or re-traumatization to family members.

Additionally, privacy was maintained by the choice of a pseudonym for each informant, that was also attached to any photograph or other artwork completed. I kept a key of the names/pseudonyms in my password-protected computer.

Potential risks and benefits.

In any research process there are inherent risks and benefits to participants. Narrative interviews within marginalized populations certainly hold the potential risk of refreshing old anger or frustrations, as well as causing re-traumatization if the interview brings up painful past experiences. Yet it is well documented that there is also therapeutic, cathartic value to speaking out and the telling of one's stories (Elliott, 2005). Hunt (2000) reported that through strategic construction of illness narratives, participants "effectively turned suffering into a social asset, and role destruction into an opportunity for personal empowerment" (p. 101). Madison (2005) confirmed this, stating "The

greatest benefit to subjects is for those who bear witness to their stories to interrogate actively and purposefully those processes that limit their health and freedom (p. 174).

While a therapeutic benefit was desired for each participant, the risk of possible re-traumatization was handled in several ways. Possible risks and benefits were reviewed in the informed consent which was read to participants, and they had the opportunity to include a trusted family member or local research partner in the interview as desired. Mechanisms for referral to local support systems were followed as suggested by community partners, such as the community mental health counselor or regional health center.

From a criticalist framework, another potential benefit is the collective recognition of the need for change and subsequent empowerment for social action. Additionally, the information gained from the data has the potential to enlighten and shift current healthcare delivery trends.

Investigator reflexivity.

We all hold conditional biases from life experiences, education and work environment. These experiences and biases in large part determine our conscious and subconscious attitudes and even actions. Lincoln and Guba (2003) urge us to, “interrogate each of our selves regarding the ways in which research efforts are shaped and staged around the binaries, contradictions, and paradoxes that form our own lives” (p. 283). Bransford (2006) refines reflexivity to critical ethnography and considers it essential that researchers continually reflect on the impact of their own personal ideology, whether the

findings challenge social injustice, and finally, whether implications for action are uncovered. Consistent examination of how we ‘walk’ in the world around us allows for personal growth and maturity. Prior to any research endeavor, critical reflection on these biases is a must, as it is important to be aware of the silent messages and signals we may be sending — and to reduce these to the greatest extent possible.

As a white, female nurse practitioner I acknowledge the careful balancing act that had to occur between my clinical and research roles. Having worked with Native American and First Nation people extensively, I struggle deeply with the injustice of the marginalization and inadequacy of healthcare that many of them face. Conversely, I recognize a certain level of personal internal frustration with individuals who choose not to engage in a treatment regimen that has been consistently shown to be effective for others. Whether related to issues of trust for who I am (or who I am not), for the clinic or healthcare system as a whole, or simply a personal lifestyle decision I do not know. Additionally, coming from a mainstream, primarily linear society demanded that I continually examine my responses and judgments as I work with those from a different worldview. Lincoln (2002) called this level of critical reflection “high quality awareness for the purpose of understanding with great discrimination subtle differences in the personal and psychological states of others. Further, such reflexivity is required to understand one’s psychological and emotional states before, during, and after the research experience” (p 337). Use of a reflective journal assisted with this balancing act, along with dependence upon the community research partners to guide, educate and challenge my assumptions.

Rigor.

The value of any study is directly linked to its methodologic rigor. Debate continues regarding appropriate terms for reliability and validity in qualitative research, yet there is no debate as to the requirement for such. Lewis (2009) stated, “repudiation of the traditional concepts and even the expanded concepts of reliability and validity offered by constructivists makes critical social science research distinctly different from that of traditionalists, modernists, and constructivists” (p. 7).

The seminal work of Lincoln and Guba (1985) discussed four terms as representative of reliability and validity in naturalistic studies for which they coined the overarching theme of trustworthiness: credibility, transferability, dependability, and confirmability. Morse, Barrett, Mayan, Olson, and Spiers, (2002) were concerned that trustworthiness is inherently a post hoc evaluation and believe that verification must occur at every stage of the research process. Rigor, to these authors, is established by investigator responsiveness, methodologic coherence, theoretical sampling and sampling adequacy, an active analytic stance, and saturation. There are many strategies that cross-over between these approaches. Operationalization criteria of each term will be reviewed specifically for pertinence to this study.

Credibility.

Credibility reflects the ability to capture the intended purpose of the study accurately (Pitney, 2004). Prolonged community engagement, trust-building, persistent observation, and triangulation of data sources provided the initial means of obtaining

data, minimizing distortion or manipulation by participants (Lincoln & Guba, 1985). While the budget for this project prevented longer than five weeks of living in the community, previous visits and familiarity with these communities promoted a more rapid entrée and deepening of relationships. Member checks or return for verification of the accuracy and intended meaning of the data was essential, as was discussion with community research partners to assure sensitivity and consistency to cultural nuances. This was accomplished throughout the duration and will continue beyond the completion of this study (Lincoln & Guba; Morse, Barrett, Mayan, Olson, & Spiers, 2002). Triangulation through multiple methods of inquiry was accomplished by participant observation and field notes, narrative interviews, aesthetics (photographs, carvings, and drawings), a thorough review of the extant research literature, and analysis of the historical contexts of the community.

Transferability.

Transferability determines the ease with which the findings of this study will be consistent in another setting, and is linked to external validity or generalizability (Pitney, 2004). Lincoln and Guba (1985) discussed transferability as requiring the provision of thick descriptions in order to locate the environment contextually. However, as society and culture are non-static, the final product will simply provide a snapshot of understanding couched within finite time and circumstance. Thus transferability is also the responsibility of anyone who uses the data to situate it appropriately within their specific context (Lincoln & Guba; Pitney).

Lewis (2009) refined transferability further in his discussion of descriptive, interpretive, and theoretical validity. In agreement with Lincoln and Guba (1985), descriptive validity demands thick description. Geertz (1973) deemed thick description as not only describing events but also the relationships and meanings that lie beneath. Interpretive validity requires the investigator to assure that it is the perspective of the participant/observed that is captured, and believes that inability to do so is a major threat to validity. Finally, theoretical validity demands congruence with stated and emerging theoretical foundations, and the flexibility to recognize and report discrepancies (Lewis; Morse, Barrett, Mayan, Olson, & Spiers, 2002).

In this critical ethnographic study it must be recognized that interviews and observations were obtained within a dynamically fluid political scene, where ownership of health clinics and treaty negotiations were ongoing. Thus readers must indeed determine transferability of results for other locales. Nonetheless, rigor was established through the use of thick descriptions in the investigator's journal and field notes, in-depth and minimally structured interviews, consistent verification of perceptions with community research partners, and consistent review of data for congruence to theoretical foundation.

Dependability and confirmability.

Dependability is determined by reliability and consistency (Pitney, 2004), and confirmability is verification that the analysis is supported by the data. Lincoln and Guba (1985) contended that there can be no dependability without credibility, and that both

dependability and confirmability is achievable through a third party review of the data and a careful audit trail. This audit trail must clearly record the process and rationale for decisions made at each stage of the research (Creswell & Plano-Clark, 2007; Lincoln & Guba; Morse, Barrett, Mayan, Olson, & Spiers, 2002; Richards, 2005). Dependability was assured by having another skilled in qualitative research audit the transcripts and subsequent theme development, as well as the audit trail decision tree. Lewis (2009), consistent with Morse et al. (2002), spoke of researcher reflexivity and responsiveness in terms of noting personal areas of bias as well as the reactivity of the Participants and Setting to the presence of the investigator. These concerns were both addressed through consistent and thorough personal journal and field notes, and augmented by peer debriefing.

Verification.

Verification implies a return to the source for confirmation. Morse, Barrett, Mayan, Olson, and Spiers, (2002) located this term within qualitative research, “verification refers to the mechanisms used during the process of research to incrementally contribute to ensuring reliability and validity and, thus, the rigor of a study” (p. 17). This demands a spiral-like process that begins with: (a) investigator responsiveness, which according to Morse et al. includes attributes of creativity, flexibility, and sensitivity, and continues with (b) coherence to research method and design, (c) concurrent collection and analysis, and (d) attention to sample adequacy and saturation while analyzing for categories, emerging themes, and contrary cases.

There is a further level of verification that must occur in a critical/transformativ e paradigm. Fine, Weis, Weseen and Wong (2003) contended that social responsibility must also be verified, and offer a series of questions designed so that “social analyses might be continually reassessed an (re)imagined:”

- 1) Have I connected the “voices” and “stories” of individuals back to the set of historic, structural, and economic relations in which they are situated?
- 2) Have I deployed multiple methods so that very different kinds of analyses can be constructed?
- 3) Have I described the mundane?
- 4) Have some ... participants reviewed the material with me and interpreted, dissented, [or] challenged my interpretations?
- 5) How far do I want to go with respect to theorizing the words of informants?
- 6) Have I considered how these data could be used for progressive, conservative, [or] repressive social policies?
- 7) Where have I backed into the passive voice and decoupled my responsibility for my interpretations?
- 8) Who am I afraid will see these analyses? Who is rendered vulnerable/responsible or exposed by these analyses?
- 9) What dreams am I having about the material presented?
- 10) To what extent has my analysis offered an alternative to the “common-sense” or dominant discourse? What challenges might very different audiences pose to the analysis presented? (pp. 198-201)

All of these criteria for methodological rigor resonate with Lincoln’s (2002) proposed/emergent criteria for doing qualitative research, all of which position the community as arbiter of quality:

- 1) Voice – articulation of who speaks, who is silenced or silent, and for what purposes. Voice is interpreted as “resistance against silence” (p. 337).
- 2) Critical subjectivity, in which the researcher and participants share a dialectic, negotiate an interpretation, and determine an action.
- 3) Reciprocity, which describes the intensive sharing of information, points of view, reflexive interpretations, and significance for research outcomes and findings.

- 4) Sacredness, which is emerging from a feminist perspective that science “has a sacred and spiritual character” (p. 339), and aims to create relationships of mutual respect, dignity, and appreciation.
- 5) Sharing the perquisites of privilege, a referent to recognition, royalties, or other benefits that may derive from the sharing-writing of research findings.

It will be difficult to actually implement, articulate, and make visible some of these criteria. However, I have attempted to honor them, and to include them in the final interpretation and analysis of the findings.

Study Limitations

Study limitations included length of engagement in the community because of budget constraints, as a more prolonged stay would have worked towards improved trust and developed increasingly collaborative relationships. Limitations also include omissions in the sample as those with positive experiences were less likely to volunteer. This is explainable by the fact that negative experiences often demand a higher degree of catharsis. In any marginalized community where uneven power differentials have been prevalent, there is a concern that the presence of the researcher produces a certain slant to the accounts. In this same way, concern for whether participants distort or manipulate reports for their own political agenda has the potential to limit the study (Lewis, 2009; Tomaselli, Dyll and Fancis, 2008). Yet, if the majority of participants consistently manipulate interviews in the same manner, this in itself creates a powerful finding.

Conclusions

The very nature of critical ethnography is the shared meaning, dissemination, and subsequent social actions from within the community that determine the level of success and favorable outcomes. As a preliminary exploration in these remote First Nations communities, where collective empowerment may seldom have been recognized, success may simply be represented by increased awareness. Later, communication and comparison with neighboring bands along the coast may encourage collaboration and assist in developing improved criteria for local healthcare delivery.

There was a deeper, underlying concern at the very foundation of this project, however. In indigenous communities it is not just the ‘telling of the story,’ but whether those with power to affect social change will ‘listen.’ Libin (2003) stated, “the question I struggle with as a white reader with a ‘foreign passport’ ... is not, therefore, Can the subaltern speak?; rather it is: (How) can the subaltern be heard?” (p. 124). While he was referring to the South African Truth and Reconciliation Commission proceedings, I believe his concern remains applicable to all marginalized groups. This question effectively shifts the responsibility directly onto the ‘hearer,’ and those who live and function in the *whitestream* must develop a new code of ethics. Potter (2002) argued that the responsibility lies in great part with those individuals with privilege or power. Jaramillo and McLaren (2008) stated these ethics involve “acquisition of certain habits of revolutionary praxis in which compassion and class struggle become spontaneous and self-sustaining” (p. 203).

Returning to the concept of the indigenous — colonizer hyphen, it is through the act of voices on each side of the hyphen, spoken in concert, that old paradigms will give way. Increasingly, collaborative and transformative research will push at the margins until boundaries of privilege dissolve. As Meyer (2008) so eloquently affirmed, “Knowledge that does not heal, bring together, challenge, surprise, encourage, or expand awareness is not part of the consciousness this world needs now” (p. 221).

CHAPTER 4

Findings

The experience of being welcomed to participate in First Nation community activities of early summer was unlike any other. As the northwest coast of BC slowly began to warm, I was witness to the emotional recollections of a life gone by, while picnicking on the beach of a remote island, once ancestral homeland. Participating in fishing and preparing the abundant salmon run, celebrating life with a wedding and later a graduation potlatch, or just sharing meals and quiet time together — all of these will remain in my memory forever. The findings presented here are based on ethnographic data collected from multiple sources as detailed in previous chapters. These experiences are framed by extremely rugged geographic isolation, where one must travel many hours in order to reach even a small community hospital. Healthcare from within the community is provided by rotating physicians who fly in on two separate afternoons a month, weather permitting. All other care is through alternating remote outpost RNs, who staff a small clinic across the bay, accessible only by boat from the village.

After a review of demographics, I will first present data by two themes considered foundational to all interviews and community conversations. Subsequently, thematic analyses by Specific Aims will broaden appreciation for the complexity of healthcare delivery in these remote communities. Finally, *Progress Along the Path* explores some of the current successful processes and thoughts of local community members on how to strengthen the system, and serve as testimony that healing and growth are occurring.



Figure 11. View from coastal logging road en route to community. Lottis, 2010.

Demographics

Interviews were divided between a remote coastal reservation and a small community, many hours distant, where services, including shopping and more extensive medical care, complete with a small hospital are provided. Many have relocated from the reservation for the improved employment opportunities available, yet retain vital and consistent connection with those who remain on-reserve.



Figure 12. Extraordinary relationship to land and sea these communities maintain, but also harsh realities of geographic isolation and confinement. Lottis, 2010.

Of the 15 formal interviews, 11 were females and four were males. Ages ranged from 21 through mid 80s, with participants' average age being 59 (Figure 13). Balance between those who live on-reserve or in the nearest service community was approximately 50%. Residence on- or off-reserve is fluid, and several maintain formal residence on-reserve, yet frequently stay in town because of work or for health reasons. One possible reason for the predominance of female interviews, aside from the fact that women may be more comfortable with a woman interviewer, is that it was early summer fish run, and many of the men were busy with the long hours of work that a good season represented.

AGE		GENDER	PRIMARY RESIDENCE *
< 30	1	F	On – Reserve
30-39	1	F	Off – Reserve
40-49	4	F (3); M (1)	On – Reserve * (1); Off – Reserve 3
50-59	1	F	On-Reserve*
60-69	3	F (2); M (1)	On – Reserve (2); Off – Reserve (1)
70-79	2	F (1); M (1)	On – Reserve*(1); Off – Reserve (1)
>80	3	F (2); M (1)	On – Reserve*

*Represents those individuals who consistently divide their time between reserve and town, either for employment or health reasons.

Table 1. Demographics.

Underlying the findings and conclusions of this study are the complex reactions to formal interviews. As an outsider, conveying the essential purpose of the study and building a quality rapport in the communities was challenging. While presentation of a verbal consent was well-received and culturally consistent, addition of the written consent and request to sign hampered, and on more than one occasion negatively impacted the developing relationship. Complicating this scenario were the cultural nuances of the one-on-one interview formats that I had chosen. While many were gracious and agreed to participate, there was obvious discomfort with the private interview with all but a few. Interestingly, as people became increasingly aware of the project, family and friends would drop by during the interview process, or join me on a beach or walking a village path to share a more private experience. There was a much greater freedom to the stories that were shared in these contexts than in those of the taped interviews. This was the time when whole families — men, women, and children, would give their version of a shared experience, and the result was a deep aggregate that began to paint a picture of the frustrations and loss so deeply embedded in their lives.

These community accounts and involvement not only formed the backdrop from which to appreciate the formal interviews, but greater than that, alluded to mistrust of formal mechanisms such as written consent and recorded conversations.



Figure 13. Traditional salmon smoked on cedar. Lottis, 2010.



Figure 14. Sharing the beauty of the ancestral island. Lottis, 2010

Thematic Interpretations

Findings revealed a spectrum of issues beyond the specific questions asked. Through iterative analytic processes, two themes were consistently found to be foundational to the responses framed by the Specific Aims in all participant interviews and community conversations. The *Legacy of Colonialism* and the *Socioeconomics of Isolation* lay the subterranean level on which subsequent themes are founded.

Legacy of colonialism.

There was not one single interview or conversation that did not relate in some way back to the trauma of residential school, either for self or family member; loss of land and traditions through relocation; or, the ongoing paternalism perceived during medical or dental encounters. The *Legacy of Colonialism* represents the importance of recognizing the situated experience and subsequent ramifications of history.

Grief.

The devastating impact of history was abundantly clear throughout the interviews. Walking along a village pathway with one of the chiefs, she related what she considered to be the biggest problem for First Nation people, “Grief ... an overwhelming sense of grief just below the surface that each and every band member carries — even the children.” For many, this sense of grief was communicated through the high substance abuse and domestic violence incidents that are prevalent issues in the lives of every family at some level. Particularly in these small communities, suicides have left a devastating aftermath of grief and loss, leaving no one untouched.

Felt by all participants to be one root cause of the underlying grief is the relatively recent history of forced attendance at residential schools. These institutions forbade the use of traditional dress, customs, language, and names, preventing return to home villages and families. ‘George,’ one of the first elders I spoke with, related his experience of residential school. He told how his grandparents took him on a canoe trip that lasted several days, arriving at “... the biggest building I’d ever seen. It made me

uncomfortable. We are used to looking across, not up.” He recollected watching the headmaster argue with his grandfather, a proud man, who never lifted his eyes from the floor, and without an explanation or good-byes, turned with his grandmother and left, stooped and beaten. Frightened, and crying for his family, ‘George’ was held down and beaten by staff members until he was silent. He related being forced to stay for the next 10 years in this institution, describing them as some of the most isolated and lonely years of his life, forced to hide his language and beliefs, with time being punctuated by frequent episodes of abuse, both physical and sexual. His has been a long journey of self-discovery and healing. Now in his 70’s, he is just beginning to claim a sense of peace, which he is attempting to share with his grandchildren and great-grandchildren.

After hearing the poignant experiences of ‘George,’ it was no surprise that every participant and community member I spoke to, commented that First Nation individuals are still deeply impacted by the effects of the residential schools. The parents or spouses who had been forced to attend now struggle with post-traumatic stress disorders, many had significant substance abuse issues to overcome, and none from this period had been exposed to traditional values of community and parenting. As we discussed the concerns around suicide and substance abuse, one woman stated:

Yeah ... and ... I feel that a lot of its caused from that ... because of what ... what the residential schools did to ... like our parents, and my husband went to residential school. Like I never went to residential school, but because my husband did and my parents did, it affected me and it affected our kids because of what my husband brought home with him from that ...

Another woman discusses her challenges with parenting, “I have no idea what a good parent looks like. I have never seen one. I didn't have one. My mom didn't have one.

My grandma didn't have one." Many grandparents step in and help out, but it has been a learned process after their own emotional healing was attended to.

All of the providers who were considered to be effective in First Nation communities had an intimate knowledge of this history. The family counselors verbalized it this way:

...because they were raised for 10-years of their life in residential school, and when they came home ... they came home to families that were completely dysfunctional ... because all of the children were always taken away. And the adults were just despondent and alcohol and all kinds of things came up ... into ... and because of residential schools ... and the abuse that went on in residential schools ... that a lot of people came home as young adults from residential schools as abusers as a result of being abused ... so it's a huge domino effect in what is functionality in the First Nations community ... so that triggers into healthcare ...that triggers into parenting ... that triggers into ... you know nutrition ... you know.... I mean that triggers into all kinds of things that just compound. So like the generation that is now in their 20s and early 30s is the first generation in almost one hundred years that are parenting their own children ... but without any reference points.

Humor.

A number of participants, particularly the elders, use humor, laughing as they told stories of extreme hardships suffered by themselves or other family members. 'Archie' and 'Mary' laughingly told a story of a time when he was hospitalized:

Mary: When he came out of there when he finally started to be stable, he was bleeding from the ears, his nose, his eyes ... he was just bleeding all over...

Archie: But that thing [IV] was going on the floor — so somehow it had disconnected ... when I had enough I guess... (Laughing).

‘Peter’ gave an account of being sutured by an intoxicated nurse in the outpatient clinic:

This was in the evening. And we got there and she had ... been ... drinking ... some ... and her hands were shaking soooo bad that she had the curved needle on the forceps ... fairly stiff little pliers ... and she (laughing) had numbed it and she was starting to stitch and she went "oops" ... and I felt a tug on my ... and one of the kids that was watching went (making expression of eyes getting wider and wider) ... "The needle disappeared ... where did it go?" ... and she said, "Oh my! My! My! It's here somewhere!" ... and she started fishing around. She lost the needle in my cut, but she found it again and finally finished pulling it up (laughing) ... but the whole time her hands were shaking, and I was thinking, "This cut is right by my eyeball ... please don't go too far astray here" ... she was able to ... she sutured it, but anyhow, that was one of my episodes...

Several of the elders spoke of being forced to move from the island that had been original tribal land, to the current village site, yet without appropriate infrastructure to sustain the people who lived there.

They used to have a well. And then a contractor came in to put in a water system, because more people were moving into the area where everybody is living now. So ... they built a pipeline from a cedar hemlock swamp ... and it was ... that's where they put a dam in ... that's where they took the water ... that water then was pumped up to tanks and ... they had a person adding chlorine off and on. But then he'd go and say ... you know ... you'd hear ... "Ah ... you guys better not..." and this would be over the VHF ... the marine radio ... "Ah ... you guys better not drink the water, I just pulled a dead deer out of the swamp here."

Others speaking of this same water system, stated that the contractor, oblivious to the harsh winter conditions, provided no protection for the pipes which frequently froze throughout the winter, leaving the community without water on a regular basis.

Paternalism.

Another face of colonialism is the ongoing paternalism. These attitudes were prevalent through the multitude of stories by each and every community member or participant regarding the dental system. Status Indians are provided dental care; however, there are very few dentists who offer this service. Experiences were related where parents

would take their children in for what was thought to be a simple filling in one tooth. They would be told to go away and come back in a few hours, at which time, multiple teeth had either been capped with silver (including front teeth), or pulled without first having taken impressions for dentures or partials. These experiences were consistent for the majority of the children and many of the adults as well. ‘Viola’ laughed and said, “Yeah — my husband went in for a toothache and came home without any teeth.” More than one participant expressed the deep sense of violation and humiliation. One woman stated “They’re doing this on purpose so that we can’t hold our heads up.”

The providers interviewed also verbalized deep frustration with the ongoing paternalism evident. One of the counselors spoke of what she had witnessed time and time again from the dental services “Once they're there, they just do whatever they want. Parents don't get a choice. Family doesn't get a choice ... and most of the kids come out ... with little silver mouths.”

Anyone has the choice of purchasing a higher quality care, such as dental work or more expensive medications, yet from all interview responses and conversations, most people were not presented with meaningful alternatives. The consistent undercurrent of these discussions related to a sense of being considered incapable of understanding – of being separated out from, and less acceptable to mainstream society.

Socioeconomics of Isolation

Directly underlying the long history of colonialism, and at the heart of every interview, the *Socioeconomics of Isolation* reveals widespread poverty, which is a strong determinant of access to, and utilization of adequate healthcare. Confounding the sense of

social isolation from mainstream society is the geographically remote nature of most BC coastal villages. With dwindling natural resources in terms of the forestry industry, fewer shellfish such as urchins and abalone, decreasing salmon runs, and the competition from the increasing sports-fishing industry, many find it challenging to bring an adequate income into the home. As the first chapter detailed, the poverty level is profound, yet expenses of living in remote locations are extremely high. Canned and highly processed foods are the norm; dairy products are extravagantly expensive with a gallon of milk fetching approximately \$12.00. Fresh fruits and vegetables are only brought in when someone has to go to town, which in itself is a full day journey. Several community members provide boat service through the inlets to the nearest roadway; however, fuel costs are high, as is the fee for this transportation. From the small bay, dirt logging roads must be traversed over very rugged terrain to reach even a small town, again with costly fuel demands and mechanical upkeep on vehicles that are pushed to the limit. Often, it is necessary to stay overnight in town, either because of weather and hazardous travel conditions, or because appointments ran long. The band does provide some monetary compensation for travel to medical appointments, however, increasingly, these stipends do not cover the full travel expenses, and many defer appropriate care because of the expense.

Consistent with many First Nation villages throughout BC, Indian and Northern Affairs Canada (INAC) moved the reserve to a much smaller location from the ancestral island that continues to hold profound importance to band members. All the conversations related to this relocation to some extent, but particularly so for the elders, for whom

it remains fresh, there were repeated comments about exploitation and conspiracy against the band. In recent years, growth of the community has been strong, and housing is no longer adequate. This, in conjunction with limited resources, has prompted many to relocate to small towns along the coast, stretching extended family systems thin, and thus decreasing another source of strength and support to the community as a whole.

These remote locations create severe challenges in terms of provision of health-care services: adequately trained personnel to staff these outpost clinics, the financial burden of flying providers in and out by seaplane and providing appropriate living conditions, and costs of durable medical goods are all prohibitive to quality and continuity of care. Accounts were told of elders who developed decubitous ulcers after incontinence briefs remained on too long, because of an insufficient monthly allocation of briefs.

A component directly related to quality of care in the outpost setting is the high cost of providing services in these remote locations. Finding providers consistently willing to work long stretches away from home, as well as the cost of providing adequate training and housing, is complicated by an extremely high turnover rate. Thus, it was not surprising to find unprofessional conduct, issues of confidentiality, culturally insensitive or ill-prepared providers all described as issues complicating developing relationships of trust, particularly notable in the remote outpost. A well-respected local outpost RN discussed her concerns about the two medical groups, each coming to the community once a month for a few hours:

One of the obstacles to good care here is that they drop in ... they drop in monthly... They don't know the people. They don't know the community, they don't know the culture ... we often get different doctors ... it's been terrible.

We get two different groups — they have opposing philosophies on chronic disease management care. It's terrible! It's been awful!

Findings by Specific Aims

The Specific Aims of the study were designed to explore and chronicle the experiences of First Nation people who live in remote communities:

- 1) to describe how First Nation people view their healthcare,
- 2) to explore how past experiences and views of healthcare influence presentation and care utilization,
- 3) to compare First Nations members' views of care received in remote outpost clinics versus care received in distant urban center settings,
- 4) to explore the impact of a healthcare provider's cultural awareness on the level of healthcare system engagement by First Nation members, and
- 5) to explore the degree to which First Nation individuals integrate traditional healing with the western healthcare system, and the prevalence of discussion and reaction to, such integration with their western healthcare provider. These aims were directed towards understanding barriers to healthcare utilization and healthcare delivery mechanisms.

1) To describe how First Nation people view their healthcare.

Views of healthcare were as varied as those who shared their stories. Individuals were reluctant to complain or reflect experiences in a negative light during “official” interviews, consistent with a cultural norm of respect for authority.

Many episodes of attentive care to the medical needs of FN community members came to light, such as a mid-40-year old gentleman who, recognized to be having an acute myocardial infarction, was air-evacuated first to a rural and then an urban center for immediate vascular intervention. The frequent suturing and wound care for traumatic injuries associated with remote living, at which most of the rural outpost nurses and physicians excel, is another example. Every participant acknowledged a few healthcare providers who they felt gave them excellent care, and who they trusted explicitly.

Despite these outstanding providers there remained a sense that First Nation people received a reduced quality of healthcare compared to their non-Native provincial counterparts. Multiple participants spoke of themselves, or family members, being under-medicated for chronic diseases such as rheumatoid arthritis, without even getting the option to purchase a higher-level, disease-modifying treatment. One gentleman shared this story of his aunt who lives on a reservation in BC:

... like from my auntie _____ with the medication that she's taking for her liver ... that being First Nations, she's a ward of the federal government. The province has a PharmaCare program, but it's for provincial residents ... so ... so this PharmaCare will provide the province's medical for expensive medicines. But because she's First Nations reserve ... she could only qualify for a ... it was supposed to do a similar type but it was the generic version of it, and it was not as effective ... she was not feeling good from it at all. And they told her (laughs) ... that "if you want the PharmaCare-provided drugs, you have to give up your First Nations status" ... you have to become a resident of BC.

Another woman told of her FN husband receiving a flimsy, poor quality sling after surgery for a broken arm, while she as a Caucasian woman received the sling he had

repeatedly requested when she had a similar surgery just a few months later. She relates the following:

And he says "It's because of the way I look" ... and I said "That doesn't make any sense, that's not right." And so last fall, I fell and dislocated my elbow. His arm was the left arm, and mine was the left arm ... totally different care. So I went in ... they did the thing ... they said we gotta put you to sleep, "We're going to pull out and put your arm back in place, and then," she said, "you'll have a sling." I woke up. I had the sling he wanted. He said "That's what I wanted, and you got the sling that I should have had from day one." So that's one thing that really bothered him. And it was right out ... blatant.

Others spoke of long waits with multiple cancellations before finally receiving non-elective surgeries such as coronary artery bypass grafts or a cholecystectomy. Each of these accounts echoed a deep sense that it would have been different had they not been indigenous.

Reinforcing these perceptions of prejudice were the frequent accounts of misdiagnoses, lack of any treatment or follow-up with complex conditions. For instance one gentleman in his mid-50's suffered cardiac arrest after a run of ventricular tachycardia. He was cardioverted and sent home by himself three hours later, without scheduled diagnostic follow-up or medication of any kind. His wife reported that they still had no idea what had caused the event or what they should do if it recurred.

Another woman told of her son who developed a severe seizure disorder in his teens:

One time my son ... we were out at my mum's for dinner and my daughter went home and she found him unconscious on the floor ... he had been having real bad headaches all day, and my daughter phoned down and said "He's on the floor, I don't know what's wrong, he won't answer." And we got up there, and we got ambulated out — we reached [hospital] about 1:00 in the morning. And they

[doctors] said, "Everything's fine — you can go home." From when we found him to when he woke up he was out for 3-½ hours. They said he had a seizure, that was his very first one, it could be his last one or the next one could be worse.

KL: Did they put him on medicine?

Yeah he did get put on something after a bit ... cause ummm ... not too long later, we got sent out again, cause when he fell he must have bit his cheek ... inside ... and it got abscessed. I phoned the nurse and said, "He woke up and he was just swollen." You couldn't even see his neck — it was just straight down. And she said "Oh he just needs to be put on meds" and then I kept phoning ... I kept phoning and saying he can't have his medication. "Well you need to make him have it." ... I said "He can't ... he can't open his mouth" ... It was so swollen he could not open ...and they couldn't understand it or something....

KL: Did the nurse see him?

No. And I finally phoned my dad and said " _____ is really sick — he's getting worse. We can't get the nurse to understand that he's not able to have his medication." So we come here and we took him back here to the hospital. And there was a really elder doctor on then and he checked him out right away and admitted him right to ICU ... He was really shocked that he survived. He said that he shouldn't have survived ... that whatever was happening was right in his brain already.

Another aspect that leads to these perceptions of inadequate healthcare is poor communication between provider and community members. Over half of the participants spoke of personally not understanding what had been discussed at the healthcare encounter, and they all spoke of elders in their family who did not understand, feeling that it would have been confrontational to ask the provider to clarify. One woman stated she believed over 90% of healthcare encounters were not understood by her people. These accounts revealed that later visits to the provider would become contentious as they were questioned as to why the treatment plan had not been followed. Repeatedly, participants stated that they or their family members simply stopped presenting to care, and emergency room visits became the method of choice for acute issues only.

‘Maxine,’ a soft-spoken elder grappled with the reasons she was misdiagnosed at the outpost clinic, ultimately resulting in a coma and a long stay in ICU. She stated, “I think that a lot of people ... and I mean that I don't know if it's native culture, but we're very quiet.” A quiet demeanor and reluctance either to ask questions or insist on a point of concern arose as the basis for miscommunication repeatedly during the interviews. For many, this was described as a sense that health providers were continually rushing, asking multiple rapid-fire questions in succession. This Yes or No form of interviewing left individuals feeling disrespected and unable to keep up. As one woman described:

Every time I've been with one of the kids it seems like they just don't even examine them — they just look in their throat, listen to their chest, give them antibiotics and that's it. They're just rushing out of there. Rushing in there. A lot of times you don't even get a chance to ask questions to the doctors.

Another woman, who goes to multiple urban specialists, describes the differences in techniques between physicians. She states that most visits are less than 10 minutes, and has lost confidence that they are interested in finding a solution to her complicated medical situation. However, she comments on the reasons she has bonded with one particular rheumatologist, where visits consistently are as described:

He took the time to like sit down and, "Let's go over this" and then he'd take the information ... like go into his office ... and he'd take all kinds of information, put it in his thing, check Internet if he had to, pull out books, and I could feel important sitting in his office. Then he'd say, "OK, let's go do a checkup." We could be in his office for an hour — like until we were done. Then he'd say "OK, I think we're done here." ... instead of just getting up and saying "See you."

This sense of being respected and heard by providers who were willing to take the time and review tests, to actually sit and discuss a medical situation and offer counseling arose repeatedly. Another woman stated, “... and he'll just sit right down and explain

everything about ... after those tests was done when my son was in there? He would explain everything and he would show me the report and everything.” The providers who had impacted care in a positive way were those who offered respect and an interest in communicating.

An elder who had spent many years in a residential school spoke of his culture being visual, with learning through direct practice and application. He spoke of the need to know the contextual reason for something, not just abstract associations, which have no meaning. He recounted an episode with a physician who stated as he wrote a prescription, “I think this is what is going on.” He refused to fill the script because the physician did not speak with the confident knowledge expected — saying *I think* rather than *I know* — thus he lost faith in the doctors’ ability and treatment.

Counselors who worked with First Nation people in the community spoke of fast-paced medical office appointments in this way:

It leaves soooo much ground uncovered, and it leaves so many people walking away feeling like they weren't listened to and that they weren't cared for, and that they're not important. And there are situations where someone walks out and calls me and tells me what's happened ... and they say ... I'll bet if you'd been there ... or I'll bet if I was non-native it would have been different.

2) To explore how past experiences and views of healthcare influence presentation and care utilization.

Analysis of the interviews revealed four major themes:

- 1) Consistent presentation for primary care issues with one of a very few trusted providers, either at the outpost clinic or in town (trusted providers),
- 2) presentation to the walk-in clinic or emergency room for acute issues only, due to mistrust of the system (presentation to emergency room),

- 3) the need to travel to larger towns to obtain adequate and/or confidential care (presentation to urban specialists), and
- 4) privacy and confidentiality issues.

Trusted providers.

There were isolated examples of successful interactions. For instance, a physician who practices on a weekly basis at a local First Nation center in town, where individuals do engage with treatment plans specifically because of his cultural sensitivity and effective communication skills. One very quiet-spoken elder grinned at me and said “He calls me his poster child” because of the success she had in gaining control of her severe diabetes, after long being considered “noncompliant.” So empowered, she now works on teaching other community members in healthy eating and improving blood-sugar control.

Multiple accounts shared the implicit trust with which those living on-reserve spoke of one particular outpost RN, who had many years of experience serving remote communities. She was described as always attentive to the needs of the people, and was respected in return for her skill as an RN. Examples given included her willingness to drive her boat across the bay to the village for emergencies, explain to patients or family members when there was confusion regarding a diagnosis or treatment plan, advocate for some with the physicians, and perhaps most importantly show respect by regularly participating in community events such as potlatches and other celebrations.

Presentation to emergency room.

Once again, despite numerous success stories, the predominant flavor was mistrust, which delayed presentation to care. One lady shared:

... 'Cause I've had ... 'cause I have gallstones and I kept having attacks. Just like every other week. And I'd go in there and he would say "Oh there's nothing wrong with you," and I was just dying ... I was hurting and everything. He said there was nothing wrong with me. So I ended up starting to go to the emergency and stuff, because I knew that they'd probably give me a needle where the pain would go away, and they kept me in there until the pain was gone.

Highly prominent throughout all conversations were the strong perceptions of discrimination in healthcare. Several individuals expressed dismay at what is frequently the first question by healthcare providers — whether they had been drinking alcohol. One woman in particular, who walks with great difficulty due to a severe degenerative myelopathy, and who has not taken alcohol in decades, continues to be faced with this stigmatization on a consistent basis. Several spoke of themselves or a family member being unwilling to return for care, after confrontations such as these. Others with chronic medical conditions have no choice in terms of presentation, yet expressed a sense of frustration and anger that respectful interactions were not a consistent part of care.

At a local mom-and-tot picnic in town, a number of the young mothers seconded one woman's experience of getting three children all under the age of five packed up, onto a bus, and into town in time for medical or dental appointments. On several occasions the buses ran late, and upon a late arrival she was turned away from the clinic, made to feel a failure and irresponsible because she didn't make the appointment on time. These women lamented the trials of raising young children with minimal support, all

while attempting to complete chores such as appointments and grocery-shopping without a vehicle, in a society where few people are without private transportation. Relating perceptions of maternal ineptitude by clinical staff, many of these young women will not present to mainstream medical clinics, but rather hold out for the overworked local First Nation Community Center provider.

Another woman explained the problem as:

... It's brutal, when someone is ill already. And part of the thing is ... I mean people do abuse the system, but part is because people are afraid of medical personnel because of having bad experiences ... It's scary to go to the doctor. So it's easier to go to emergency or a walk-in clinic, where you're not going to see someone again ... and that way if they treat you badly, you don't have to see them again, but they might be able to figure it out and then you're done. Rather than go to a family doctor who you're going to see every time and you don't ever know if they're going to be nice to you or not nice to you ... and if they're not nice to you ... then I don't want to ever go back there again. Now what do I do? So a lot of people just don't bother having a family doctor ... they go to someone that they don't have to see again.

Additionally, there is a sense that clinics do not provide complete care. It is typically a rapid, 10-minute appointment, and the diagnostic process may take days to weeks, if it gets completed at all. Physicians may give a slip of paper to obtain blood work or imaging, but there can be challenges in transportation to the lab, a misplaced requisition, or simply confusion with laboratory staff or queues. Thus care does not feel as comprehensive. Rather, presenting to the emergency room provides the perception of a higher level of service.

I found that going to the emergency they help you better there because they do tests on you and stuff. It's like when I had my son this weekend saying he was having a hard time breathing "It feels like there's something heavy on my chest." We brought him to the emergency and they did all the heart machine — they put

stuff all over him, then they listened to his uh ... I mean checked his blood pressure, then they x-rayed him.

KL: ... and if he had gone into the clinic what do you think would have happened?

I think they probably would have told us it was a cold or something. Because I know that our doctor wouldn't have thought it was serious.

Presentation to urban specialists.

Questioning whether specialists worked as an integrated team on complex cases, one woman expressed her frustration with her multiple physician's inability to communicate together. "That's what makes me so angry — it's just that they all seem so separated." She went on to describe how she felt caught in the middle as one would prescribe a medication, and the other would discontinue it, without ever discussing an overall treatment plan that she could begin to improve on. She and family members described her gradual decline in health over the years, and feeling of hopelessness that the doctors will ever be able to "get it together" enough to change the course of her disease.

And she [doctor] doesn't do anything. But I've been seeing her for YEARS now, and ... I told her before ... Try anything! I'm willing to try anything ... you know ... just help me. I can be a guinea pig if you want. But she never changes ... it's like whatever Dr. _____ [rheumatologist] approves, Dr. _____ doesn't. Cause it goes through _____ [one specialist], then _____ [another specialist], then _____ [another specialist] says no. And that's where the process stops ... AGAIN!

The family went on to express frustration with clinic and hospital staff who had no concept of how difficult it was to come to these appointments, and who would tell them that an appointment had been cancelled when they were standing at the counter, not recognizing that it had taken two days of hard travel and significant expense to get there.

Mistrust of the system was also based on a sense of non-disclosure on the part of the medical system. Two women told of research studies being done in their families after deaths had occurred reportedly from rare diseases. Permission was given, multiple blood tests drawn, yet neither of these women recalled any family member being given information on the study findings.

Privacy and confidentiality.

Privacy and confidentiality were hot topics during the interviews, particularly for counseling. In these small communities individuals are well aware of their neighbor's stories, and it takes only a phrase or two to reveal the *who* and *what* of a meeting. As one woman shared when asked about counselors in the area:

... a lot of people don't trust 'em because they break the confidentiality rules. Yeah. I had experience with that myself, where I went in one door, and by the time I got to the other door after my meeting with the counselor, everybody knew in there what I had just talked to her about.

Perspectives on mental health counseling gave a unique view to that discovered in the literature. One man shared the tribe's previously held conviction towards mental health:

And this is what we were dealing with ... is that when there was something wrong and they mentioned mental ... 'cause our language it's the one that made a mistake ... the way you interpret our language and mental illness is that it means crazy ... there's no other word you can use ... so nobody wanted to be termed crazy!

This gentleman indicated that attitudes are beginning to shift as individuals gain a deeper understanding of mental health issues. Multiple participants spoke of the importance that excellent counseling services had played in their recovery from post-traumatic-stress disorder and depression, typically related to issues surrounding residential school.

3) To describe First Nation members' views of care in remote outpost clinics versus that received in distant urban center settings.

The options for the First Nation people who live on this isolated reservation are limited. Several outpost nurses and physicians who had developed strong relationships, were excellent healthcare providers, and served invaluable and well-respected roles in the community. However, these providers were few and the gaps were significant.



Figure 15. Example of the close quarters and aging condition of homes in this community. Lottis, 2010.

There is a small outpost clinic run by the provincial health system a short boat-ride away, and bimonthly physician visits in the community itself, each of which lasts only a few hours. While a few nurses will come on the reservation for emergency evaluations, they come at their own discretion; many are uncomfortable and refuse. In an emergency situation, community members then carry the injured or ill person by stretcher down to the dock, load them on a boat, ride over to the outpost clinic, and carry them up

the ramp where they are evaluated in the clinic. At that point, if transportation to an urban center is required, weather determines when and if a seaplane will come to the dock, or they must be carried back across the bay by boat, stabilized at home as best as able, and then transported up a very steep hill to the only possible helicopter landing site, again as weather allows. The expense of leaving the community is enormous for patient and family members, who must pay for the boat-ride to the nearest road if they do not own a boat, absorb the fuel costs associated with the large trucks which are the only way to navigate the treacherous roads, and finally pay for motel and food costs while staying away from home.

Experiences people shared ranged from humorous to horrifying as they told stories unique to isolated living. 'Peter' told of a highly skilled outpost nurse with a severe alcohol abuse problem. One evening while playing field hockey with some of the young boys, he suffered a head laceration. Laughing, he recalled his fear while the boys all stood around laying bets on whether he would suffer eye damage due to the shaking of this intoxicated nurse while suturing his brow.

Another recalls her experience as a teenager with the local clinic and her concerns with issues of privacy and confidentiality:

I went on birth control when I was a teenager ... and I went on my own ... and you know it was discussed as though ... and for me I was mortified because people were finding out about this, and ... "Oh my God!"

KL: How could people have found out?

But that's just it! When it's only between you and your nurse, it's supposed to be confidential ... but ... unless it happens to be mentioned to one person and then it's passed on to the next ... and so that definitely ... I mean, you know ... at the time it was mortifying, but I'd already gone in ... after that I came out to my family doctor to get it, because you know...

Responsibilities of the outpost nurses include triage, and they will often arrange transport to medical centers based on acuity, sending a full report and past medical history at the time of transfer. One woman told of a family member being transported without a report to a small rural hospital, where she was allowed to languish for weeks, thinking an illness was related to drug abuse, missing the underlying renal failure.

Another example of communication breakdown surfaced as ‘Vivian’ recounted her terror as her daughter bled:

... my daughter had a miscarriage, and, ummm I phoned the outpost and I said "I think my daughter's having a miscarriage." And they said "The doctor's in town, why don't you call him?" So I phoned the clinic, got a hold of the doctor and he says, "Well give her a couple of Tylenol and you know — she should be fine." And I said "But she's having a miscarriage," and I've never ever had one so I didn't know what to expect ... So when she had the miscarriage they said "Well bring it over here and we'll send it away and whatever," and I said "Okay." So we did that, and I went to work and I told my dad, "My daughter just had a miscarriage ... and she was *really* bleeding." And I told the nurse and she said "Oh that's normal, that will just happen." And then they phoned me at work and said, "You need to come home because she's really, really, really bleeding yet." So I went and told my Auntie and she said "I'll get ready, we'll go to town [hospital]"

... So we took her out, by ourselves... and we had no money or nothing, we just took off and went and ummm ... he did the ... whatever they do ... the scraping? He did that ... and he didn't think everything was out yet, so he wanted her to stay around a few more days. So we phoned home and said "We need help, we need a room, we need meals." And they said "Well, there was no reason for you to go because the doctor was here in town and he saw her." And I said "No he didn't see her. He said give her two Tylenol but that's all. That's not seeing her" ... Later that night she started hemorrhaging more and we had to bring her back to the hospital, and they dealt with her there. She was there for a bit.

In almost every account, problems arose because the correct questions either were not asked, or not understood. In this band of approximately 500 members, whether living on- or off-reservation, all those who shared their experiences included stories of immediate friends or family who had died because of missed diagnoses or delays in treatment.

An elder echoed the recurring issue of accurate triage and timeliness:

We've got one nurse that she knows what she's doing, and then they stay there what ... two months at a time ... and the one is not as good as the older one. _____ can do anything. But it takes her awhile to get things going, yeah? We've had two guys that just had a heart attack right at home, eh? Because they didn't send them away right away.

One story repeatedly arose, as the community was still reeling from the loss of a well-respected elder.

_____ was our preacher. And he complained about his heart. And the next day he was gone. They didn't send him away for a check up or something. He kept telling his wife, "Something here is hurting away," and they gave him some heart-burn medicine ... and the next time he was on the floor and he died.

Another participant gave voice to what several circled around — the concern that a wait-and-see approach left community members at risk.

Like a lot of times when there is something happening with someone they just wait ... ahhh ... probably thinking of the expense of sending them out or something. But I noticed that a lot of times ... the situation gets too bad before they help them.

In all the stories related, what quickly became obvious was that successful outcomes were related to a family member acting as advocate for the patients, either by personally transporting them to town or independently calling in medical flight teams.

Family advocacy also improved outcomes in the rural hospital setting with rapid evaluation and transfer to urban centers for advanced treatment. People felt it occurred only because family members would not settle for less.

Each village has an official Community Health Representative from the band with a broad job description that includes advocacy and triage. This role was created to facilitate rapid transfer to urban centers, assistance with expenses while away, and advocacy support with healthcare institutions and providers. However, comments made during the interviews revealed that the responsibilities are too widespread, with inadequate training for the listed job description, and far too many duties for one person to accomplish. The position has thus become primarily a clerical role, arranging travel and healthcare visits to urban centers, and submitting documents for some monetary assistance. A number of people voiced the sense that this position should be split into two separate roles, clerical and clinical.

Numerous accounts revealed the mixed emotions that accompanied care in urban centers. While there is full belief and expectation that city hospitals provide effective treatments, in a communal culture where extended-family inter-dependence is essential to survival, the process of supporting a loved one through surgery or treatments is daunting. While baking bread, 'Dolores' shared the story of her husband's emergency transfer and stay in an urban cardiac hospital.

Just the waiting around was the hardest ... three weeks I think it was. He got bumped a couple of times. The first week they were just doing tests. And ah I went down and they said they were going to do the surgery on the Monday. I went down on the Friday. And he got bumped that time. Somebody else got more emergency (small laugh). And then we waited again another five days or some-

thing and he was going to go back ... then got bumped again. He got to the operating room door ... and he still got bumped ... Yeah. Ahhhhh, he was getting really frustrated. He wanted to just leave. He didn't want to stay and wait for it ... (laughing) ... "You can call me when you have time for me" he said. Then he ... they realized that he was gonna ... that he wasn't just saying that he was gonna leave. And they ... "Oh we'll put you in very first thing" ... so that's what they did. Yeah.

KL: Did he have an open heart?

Open heart. Yeah. Five bypasses.

Experiences were shared that included deep loneliness, fear, and even hunger as funds limited access to food and safe lodging. Ineffective communication on the part of urban physicians left many confused as to the medical process or expected outcomes, which was voiced as increased fear. Some individuals stayed in the city alone to receive treatments, either because the financial burden was too great, or extended family responsibilities forced return of a spouse or parent back to the reservation.

4) To explore the impact of a healthcare provider's cultural awareness on the level of engagement by First Nation members within the system.

One of the most profound strengths of First Nation culture is not only the strong commitment to extended family and community, but to one's ancestry. 'George' shared that as First Nations:

You don't look to the future to see what you can become ... you look to your past to see what has made you who you are. And so you are a product of your past. And that is just a part of everyone's thought and identity.

He went on to say "Without connection we are nothing." The echo of this theme continued throughout all interviews where participants shared struggles in keeping families

together, attempting to make it financially, caring for the children and the elders, and for those with major depression and substance abuse issues. Both the wedding and the graduation celebrations were poignant testimony to this concept as extended family and community members stood and spoke in support of, and commitment to the celebrants, thus forging family units in an ever-stronger bond.

One of the outpost nurses spoke of being witness to this powerful community outreach after a near-drowning incident involving several fishermen. Within hours, the entire village had rallied to create a *Celebration of Life*, provided a feast and gifts for those involved, and allowed a platform from which those involved could debrief, celebrating those who had been saved as well as those involved in the rescue. These formal *Celebrations of Life* are consistently given for those who have suffered some life-threatening event, reminding all involved as one elder put it “of the happiness in just being alive – of the sun and the rain on your skin.”

This outlook, recognizing the past and celebrating the present in quiet, non-confrontational ways sometimes confounds interactions with the healthcare system. As previous findings have shown, the level of cultural sensitivity on the part of the healthcare provider, and their ability to create a trusting relationship has profound implications in the way First Nation people respond to care. Generalized assumptions are a significant barrier, such as belief of widespread substance abuse behaviors. More insidious behavioral assumptions are consistent with the following woman’s story of presenting to clinic in early pregnancy. She laughingly tells of the physician who asked, “I wonder how come it took you so long to get ...? I mean you had so much problems

before getting pregnant." I said "I was not with anyone, so how could I have gotten pregnant?" She went on to voice humiliation that he had assumed she was sexually active without having the courtesy of clarifying her situation.

Many FN individuals related discomfort in questioning the healthcare providers or feeling belittled by the assumptions made. 'Edith' noted, "Sometimes it's really hard to talk to doctors. Like when you go for an appointment and it looks like they're always rushing — they're just wanting you to get out of there as quick as possible."

Conversations with a nurse, physician, and counselors, each known for their cultural sensitivity and attunement, shed the most light on this challenging topic. One couple, who have served as counselors for some 30 years, and, having been adopted into a Native family, spoke of the countless times they would accompany a FN individual to a clinic visit or emergency room. He told of one instance:

The nurse was really rude to him ... she ignored ... he was in REALLY bad pain ... he had an abscessed tooth, and basically she was saying, well that's what happens when you don't take care of yourself. But she was directing a lot to me and talking about him to me directly, while he was right there. She was just very condescending to him ... but so I was realizing that being the 'white person' and bringing in somebody First Nations ... like the assumption was that they wouldn't understand what they were being talked to about, and so that's why I was talked to.

His wife adds:

So it would be like I was translating, but there was no need to translate, because their English is perfect! I mean finally ... that happened for years, and so a lot of times, people would call us and say "We need a ride to the hospital," but what they were asking was "come go with me so that you can help talk to the doctors." It wasn't that they physically needed to get up there as much as they needed ... they needed an advocate while they were there.

A physician, with years of experience with FN bands in the far North of BC, spoke of the importance of provider awareness regarding the history that these communities have undergone:

And when you're providing medical care for people who have gone through so much ... ah ... the people up in this area, their land was all flooded in the creation of the reservoir, so they lost ... well I mean they lost their villages, their burial grounds, their houses ... everything was taken ... and then certainly with the residential school process ... And I think more than for the people I've provided care to in the past, I think it's really, really, really important to establish relationships and levels of understanding and mutual respect, and until you do that, ah ... medical care is this sort of band-aid fix, and all you do is sort of scrape the surface.

This doctor admitted that despite excellent clinical skills, many medical providers were not only ignorant of the socioeconomic and historical realities of FN people, but held stereotypical convictions, both of which limited the ability to provide high quality care. He spoke at length about the importance of establishing healthy relationships as the only way to offer effective care.

One essential building block of any relationship is communication, and the counselor commented:

If you're in a hurry ... if you're in a rush ... that in itself will shut people down from giving you questions because they feel like they're not important enough to impose upon your time. Whereas in non-Native, it's like we stand up and we go "Excuse me... this is what I need from you." ... We're not looking and going OK ... he's edging towards the door ... he wants to leave. Yet a First Nations person will *look* that he's just looking at the door, and will quit talking because he needs to leave. So I think patience is a huge big thing. But I'm not a healthcare provider, so I don't know what it's like to be on the other side of the room.

The woman who shared the experience of taking her teenage son to the ER, went on to share the rest of this experience. The physician showed cultural sensitivity by taking the time to explain to this young man what was going on, and what he believed

was the cause of his symptoms. “It was a really good speech because my son wouldn't listen when I said that, but he listened to the doctor and he's taking him seriously.”

5) To explore the degree to which First Nation individuals integrate traditional healing with the Western healthcare system, and the prevalence of discussion and reaction to such integration with the healthcare provider.

Every participant held the knowledge of traditional herbs, barks, and remedies. Many had experienced the healing properties of these treatments in years past. However, no one admitted to still using these preparations. Two women told of physicians who had told family members to stop all herbal preparations while being on allopathic treatments. In each case they were never asked whether traditional medicines were being used, and if so, what they were taking and why. The physician simply told them that they should discontinue any traditional treatments. Many of the participants noted specific individuals in each band who they knew to be knowledge keepers, all were elders, and many had since passed on.



Figure 16. Contemplative walking along the beach of an ancestral island, always on the lookout for rare shells for ceremonial regalia, or a prized shellfish, considered essential to health. Lottis, 2010.

‘Pauline’ offered another solution to the apparent loss of traditional therapies.

Pauline: I don't know if anybody does it around here ... but I had a friend who was doing it. She'd go into the woods and collect what she needed to make her medicine. She passed away a couple of years ago. But I don't think anybody goes out and collects anything around here. We hear about it ... people talk about "Oh we used to use this and this, but nobody really does it." _____ (husband) would know more about it than I do, cause I was raised elsewhere ... I wasn't raised here.

KL: Where are you from?

Pauline: From here, but I went to rez school and spent a lot of time away from home, so didn't get taught all those itty bitty things. _____ (husband) was raised here mostly by his grandparents, so he knows more about this stuff, more than I do (laughing).

An elderly couple share in the telling of her story.

Archie: What did you have when you couldn't move out of bed? Arthritis or something? What was it?

Mary: Arthritis in my spine. That was the worst thing. I could never get off the bed and sit up? I'd have to slide to just stand up...

Archie: Yeah, and she was quite young yet, eh?

Mary: And it was really simple ... my mother told me ... go to _____ Island, there's a tree there. Was it _____ island? What was it?

Archie: _____ (named tree) ... yeah.

Mary: Wild _____ — that's it — the bark ... Go in the morning she said ... go early in the morning ... we took you eh? (speaking to daughter) ... So we did all that. And it was just close to the water's edge ... so while we were going there I was praying that it was gonna work. But ah ... I went and stuffed a sandwich bag full, and she told me to let it sit for four days, or else boil it for 10 minutes. So I did all that. And she said you don't drink too much. A medicine cup a doctor gives ... just half of that ... If you take too much, you'd get diarrhea (laughs) ... So I did that, I think it was a gallon I made out of that. Took it every morning ... was it 2 months? something like that? (family concurs) ... and there was no more arthritis.

Archie: Yeah. She couldn't even get off the bed ... she'd have to roll off ... then she was better.

Another elder shared hilarious stories of a few well-known medicinals along the

BC coast:

... And then seaweed. You wouldn't believe seaweed helps too if a person has a hemorrhage ... Yeah. My relative ... was telling us that he had really bad — couldn't stop bleeding, so ... it's a funny story (giggles). His wife took the seaweed, wet it, and put it in his rear end — put it in. I guess he hollered at his wife, "You don't have to put the whole sack of seaweed in" (everyone laughs for quite some time). Ah geez — for years I've said "You're lying on that one" and they say, "No it's true!" But it stopped it too, it stopped the bleeding eh? Yeah. Yeah.

In another story she told of having given an herbal tea to the local minister who suffered with arthritis, and the humor of miscommunication and subtle play on word pronunciation.

... the tea from the _____ heals people, and we call it *wekl'assh* ... we call it *wekl'assh* ... and the minister says "weak ass heals you" ... "weak ass" (as she giggles away). He couldn't understand ... (everyone laughs) ... "weak ass heals you!"

In each and every account, a deep belief in the validity and efficacy of traditional medicine was obvious, yet at the same time there was an element of sadness and loss during the entire discussion. There was a sense that the ability and freedom to use traditional medicine had eroded along with other indigenous customs, and that to walk in the non-indigenous world meant to leave these traditional customs behind. Several spoke of being unaware of the location of necessary ingredients, "We always used Indian medicine up there, but down here we don't know wheres to find it." Others spoke of the passing of the community members who held the knowledge, and still others commented that some of the most effective treatments represented over-used resources that were challenging to obtain.

Progress Along the Path

Within these First Nation communities there is vast room for improvement of healthcare services, yet there are many things that are positive. Essential to improvement of the healthcare system is the recognition that it will take responsibility and work from all directions — from the First Nation people themselves, as well as the medical, educational and governmental establishments.

Many participants spoke of themselves and family members who had claimed mastery over traumas they believed to be a direct result of ongoing colonialism. These manifested in multiple ways such as anger, violence, substance abuse and overwhelming grief.



Figure 17. Cedar carving: Transformation. Lottis, 2010.

An elder who had shared the story of his long recovery from the traumas of residential school, offered this cedar carving as a gift, as he explained the road of forgiveness and personal transformation that he had undergone. He described the transformation of the killer whale, which he identified as being a much more solitary creature of the ocean, into that of a wolf, which is better acclimated to living on land and in a structured society. Integrated within this transformation is the spirit of the eagle, which offers a sense of vision and wisdom.

The cultural sensitivity of the *whitestream* in conjunction with political action, improved advocacy, and communication on the part of First Nation people and com-

mitted outsiders — all are components that represent healing of the past and improved services. Healthcare advocacy is extremely important, and the families where specific individuals intervened on behalf of parents, siblings, or children have navigated the experience with positive outcomes.

Advocacy.

One elder describes her grand-daughter as her advocate with the doctors, “I tell them to talk to Sara or I have somebody else to be with me, ‘cause sometimes I can't understand things that they tells me.” Another young woman tells of the complicated delivery of her first child, when her normally soft-spoken mother intervened when outpost providers were not responding to a deteriorating situation. “And that's when mum stepped in, and mum was head of the coast guard auxiliary at the time, and just called in and had me Medevac'd out (laughing) just like, "You're not touching my kid anymore!” Another gentleman tells of having chest pain while in town, and his teenage son saved his life by refusing to let him go anywhere but the hospital, where he was immediately transported to an urban cardiac center for revascularization.

Cultural and contextual awareness.

While the importance of advocacy and assertiveness on the part of First Nation individuals cannot be underestimated, it also takes cultural sensitivity on the part of the providers. Appreciation for the historical context of First Nation people and the importance of respectful conversation is vital to every interaction. The successful providers who were either interviewed or spoken of by participants, without fail recognized the underlying grief and loss that accompanies many physical conditions, and put significant effort

into developing relationships. One physician explained the multiple issues around remote outpost care and the governmental push towards chronic disease models this way:

But even if you look at the aboriginal population where the stats on those illnesses are quite bad ... yeah ... that is just a symptom. You know, over-eating and alcoholism and drug use is ... I would really argue that they are symptoms of a much larger problem. And until you address the deeper issues, we are wasting our time making people feel guilty about not adhering to the diet and the insulin and the sugar testing that we're suggesting ... or their compliance with medications ... You know the issues are the depression, the suicide, and the drug use and the alcoholism and the ongoing sexual abuse towards children. And to deal with those things, you know, you can't ... you can't make a chronic disease model. You know you have to develop relationships with people, so people can trust you ... and they'll let you in and help you with those things. And so, I think if we're EVER going to address those issues, the model that we're using right now will never, ever work ... there's no way.

This physician spoke of his approach to care:

...but going out to people's camps, and taking my family out and camping with people, and spending time doing traditional activities ... and making hundreds of mistakes and making a fool of myself ... but I think that's how you establish relationships ... And then! And then I think you have the right ... a very, very small right ... but you have somewhat of a right to be there then ... I think. And then, that gives you the capacity to be there for people ... you know when a child dies ... because then you're not an outsider anymore, you're a community member. You're not a band member, you never will be ... but you are a community member, and so I think that does give you a greater capacity to provide medical care.

There are providers who are investing the time it takes to create lasting relationships of trust. First Nation people are advocating with healthcare providers for family members, claiming empowerment over chronic diseases by modifying lifestyle habits, healing from depression and grief with the help of counseling, acceptance and forgiveness, and quietly sharing these techniques of success with others. Tribal councils are beginning to run cultural sensitivity classes for local providers and training for band

members to care for elders at home. Drug and alcohol counselors come to the community on a regular basis. Some of the outpost nurses provide family planning education, healthy dietary choices, meal-planning, and weight-loss strategies. All of this and more is happening in select cases and with varying levels of success, yet without a doubt it needs to be grown and encouraged from every angle.



Figure 18. Vision of the Eagle. Lottis, 2010.

CHAPTER 5

The time spent on the BC coast in these communities was a powerful demonstration of the richness and beauty of the First Nation culture. During these interviews, and in following iterations of analyses, I have laughed with the memory of shared jokes and humor, cried with sorrow at the challenges and losses so many have had to face, and felt deep anger at the needless frustrations, and even deaths, poor communication and lack of follow-through have caused.

Summary of Findings

Findings revealed many positive aspects of healthcare delivery to First Nation people in the small coastal communities of BC. Nonetheless, multiple areas for program development were in evidence. A brief summary of thematic findings from Chapter Four will highlight conclusions that suggest areas for improvement, as well as a brief commentary on cultural nuances that came up during the interview processes. Throughout the interviews, participants offered specific suggestions for program development or needed improvements, and these offer implications for healthcare. Following this discussion, reflections on methodology, including inherent strengths and limitations, as well as implications for further research are presented.

As is frequently the case in qualitative studies, the overlap between themes is great, yet each holds unique attributes in the overall equation. Findings were consistent with all five key areas of major disparities delineated by Andrulis (2003), including: a) access, b) differences in quality, c) perceptions and realities, d) barriers to

communication and, e) genetics. These key points of disparities interweave throughout the themes, and assist to focus on essential challenges as well as possible solutions.

Legacy of colonialism.

The *Legacy of Colonialism* clearly demonstrated the ongoing ordeals that these First Nation bands are facing. As one of the elders stated, “We are a product of our past.” The past for FN individuals has been rife with suffering, separation, and loss — most at the hands of the *whitestream*. Residential schools were directly responsible for loss of the cultural knowledge passed generationally through family lines; loss of the experience of parenting and being parented; and, loss of identity — all compounded by abuse and trauma. Relocation of reservations away from original tribal land, with inferior or inadequate infrastructure to support entire communities has created a sense of conspiracy, particularly among the elders, for whom it remains fresh.

A major common denominator of distress in these interviews was that of the dental care. Many are not able to break free financially from the ongoing paternalism and prejudice that is associated with silver crowns and dentures, the system’s norm for First Nation members. The associated impact this has on self-confidence was mentioned repeatedly, and this adds to the cycle of grief, low self-esteem, and limited educational and employment opportunities which effectively perpetuate marginalization to the periphery of mainstream society, along with attendant opportunities.

At the heart of the profound grief mentioned by the band chief is the concept of cumulative harms. Even if we set aside the well-documented and profound trauma of

colonialism, the current harms continue to impact FN people to this day. These harms include inadequate dental care, paternalistic attitudes of dentists and doctors, ignorance regarding cultural history and communication styles on the part of providers, inadequate training for providers within the context of remote outpost living, decreased or challenging access to high quality care, and blocked opportunities in education, employment, and housing. These factors have led to diminishment of both cultural self-identity and pride, which should be the natural birthright of each and every First Nation member.

To return to the work of Harvey (1999), these forms of civilized oppression diminish status and exert control, with little recourse by community members to improve the situation due to the vast differences in power differentials. Institutional refusal to change is an integral part of the cumulative harms of civilized oppression by way of blocked opportunities, and indeed must be regarded as a deeply moral issue. I would challenge healthcare administration and education (nursing, medical and dental) to interrogate programs at a national and international level, and ethically question methods which favor the *whitestream*.

Hunter (2002), noted the limited studies available on the traumatic residue of colonization with indigenous, commenting on the continued generational trauma that is still being suffered from dissimilation of family structure. Participants in this study remarked time after time how either the participant themselves, a spouse, or a parent had been taken from their communities. One woman stated, "I'm not from here," yet she had been born on that reservation, and returned to it as a married woman. This statement portrayed the sense of discontinuity that so many referred to.

Consistent in all of these interviews was that the subject of everyone's humor appeared to be based in a hopelessness, whether due to poor quality, inattentive medical care, or *whitestream* businesses that were perceived to profit at the community's expense. After reading the transcripts, one of the community research partners, after seeing how often laughter was transcribed, acknowledged the importance of humor as a means of hiding the deep grief and hopelessness that lies just below the surface. However, use of humor is multifactorial, and may also provide an emotional and physiologic protective mechanism. There is significant literature recognizing the healing power of laughter (Buxman, 2000; Boone, Hansen, & Erlandson, 2000; Miller, Mangano, Beach, Kop, & Vogel, 2010; Mooney, 2000; Schwartz & Saunders, 2010), and perhaps these elders have more yet to teach us, as it relates to claiming humor in our lives. Further exploration of this fascinating topic is warranted.

Socioeconomics of isolation.

The *Socioeconomics of Isolation* highlight some of the challenges specific to those who live in remote areas, where cost of living is very high, yet opportunities and income potential quite limited. Added to this are limited access to higher education opportunities due to financial constraints, and the reality of small village schools being unable to compete academically with mainstream institutions. The young lady who had just graduated from high school during my time in the community was preparing to attend an urban university. She was being financially assisted by multiple community members, not just family, in order to make this dream a reality. There was a strong sense

of excitement around her plans, as comparatively few young people had made the decision to obtain post-secondary education.

The data on poverty for the majority of First Nation people is appalling, and living remotely compounds many of these financial issues. Consistent with many reservations, there is inadequate housing or building sites available for the growing population, and thus many must live away from home. Fishing and logging provide the primary incomes, however decreasing natural resources, as well as competition from sports fisherman and larger commercial concerns have made this a near impossibility for all but a few.

The challenges of a socioeconomic prison, where isolation limits income potential yet results in an extremely high cost of living preclude options otherwise available. Those who have left for larger cities in order to gain brighter employment opportunities leave behind the supportive community that has been a traditional mainstay, and thus suffer a far more insidious isolation.

From a health perspective, poverty then impacts ability to return for follow-up care, to purchase the medicine(s) appropriate to the condition, or even obtain an adequate quantity of durable medical goods. Finances obviously affect dietary choices, as highly processed and high-fat fast foods are typically much less expensive than the fresh fruits, vegetables, meat, and seafood that would offer a healthier choice. Transportation and storage compounds the nutritional challenges of remote living. Extremely mountainous

terrain, along with harsh and long winters, creates costly dilemmas to gardening or hothouse alternatives.

Specific aim #1.

In the first Specific Aim I explored First Nation views of healthcare, and findings revealed mixed appreciation for healthcare providers. In cases where satisfaction with healthcare was high, one of two things was apparent: First, the provider was skilled in communication and sensitive to the cultural differences and history of FN individuals, or second, family members assertively advocated on behalf of an individual in the healthcare encounters.

Examples of trusted providers includes one outpost nurse who held a talking circle with the elders when she first came to the community, asking them about community priorities and explaining her role as outpost RN. The fact that she had taken the time to ask and listen, as well as the continuity of her many years in the same community provides a firm foundation, and respect was evident in every conversation.

For at least half of the participants, if it had not been for family members acting as advocates, the situation may have had severe consequences, if not been fatal. Dependence on each other, both extended family and neighbors, surpassed the trust placed in the healthcare system, and was related by stories of the multiple experiences that cemented these relationships. The plethora of literature relating to advocacy in healthcare amplifies the empowerment achievable for individuals, families, and communities. Improved advocacy is noted to be crucial in providing care to marginalized populations, whether

provided by the healthcare system, or integral to the family unit (Baffour, Jones, & Contreras, 2006; McCammom, Spencer, & Friesen, 2001; Schooley, Mundt, Wagner, Fullerton, & O'Donnell, 2009; Shield, Wetle, Teno, Miller, & Welch, L.C., 2010).

Overshadowing the many positive experiences were perceptions of overt as well as indirect prejudice, and an overwhelming lack of cultural awareness or sensitivity on the part of providers. Participants spoke of episodes that include communication breakdown, rushing through encounters, and general lack of respect, resulting in fractured continuity and missed opportunities in healthcare. This type of encounter continues to promote an uneven power differential, toxic to the development of relationships.

There is significant data linking trust in the healthcare encounter with increased satisfaction and positive outcomes (Alazri & Neal, 2003; Auerbach, Kiesler, Wartella, Rausch, Ward, & Ivatury, 2005). Conversely, limited trust with perceptions of discrimination or prejudice adversely affect healthcare outcomes (Facione & Facione, 2007; Kennedy, Mathis, & Woods, 2007; Lindström, 2006; Williams, Neighbors, & Jackson, 2008; Wills, Mury, Brody, Gibbon, Gerrard, Walker, & AINETTE, 2007). Levitt and Weldon (2005) found that trust was based on past experience and level of reciprocity in a relationship. Garrouette, Kunovich, Jacobsen and Goldberg (2004) noted that level of identification with ethnicity was inversely correlated to healthcare satisfaction.

Specific aim #2.

The second Specific Aim revealed how past experiences influenced presentation to care, and multiple circumstances affected where, and with whom, individuals would

present. As stated previously, there are excellent providers who empower patients to take control of their own medical issues, and, educated with respect, many have done just that. For those individuals, presenting to care was an opportunity to demonstrate continuing improvement, they felt safe sharing other problems, and regular presentation to the clinic was not an issue. However, these accounts were in the minority, and predominantly, stories circled around presentation to the emergency room for acute care issues only.

Reasons for the avoidance of primary care clinics or specialists included a sense of not being heard or respected, difficulty in understanding, and a sense that there was no time or willingness to explain. Disrespectful interactions preclude further involvement in the healthcare encounter. Conversations indicated a sense of anxiety around presentation to clinics or hospitals, and thus visits were postponed or ignored. Emergency room visits for high-acuity issues are the norm for many participants interviewed, and ER protocols that include full diagnostic work-ups leave individuals with the perception of a higher quality of care. These findings were consistent with the literature, where there is a higher percentage of ethnic minority individuals who use the ER as the primary source of care, although the reasons for this appear complex and deserve additional study (Costa, Sullivan, Walker, & Robinson, 2008; Mosen, Schatz, Gold, Mularski, Wong, & Bellows, 2010; Walls, Rhodes, & Kennedy, 2002).

For those with complicated medical diagnoses requiring multiple specialists, several components affected consistent presentation. These included the economics of traveling and staying in urban centers for medical appointments, as well as the challenges

of understanding specialist orders and instructions. Most importantly, the poor communication between specialists or with primary care prevents continuity and leaves many not only discouraged, but with a sense of hopelessness that they would ever be well.

Accounts in this study confirmed the work of Browne (2005), who discussed hospital nurses' stereotyping of FN individuals. Numerous participants revealed a sense of stigmatization when presenting to clinics or hospitals, noting assumptions of intoxication, ineptitude in parenting, or inability to comprehend.

Stereotypical assumptions are insidious, with a brutal effect. Without contextual knowledge of an individual's situation, a provider is unable to explore the social and political realities underlying the root of many medical conditions. The stigmatization of widespread alcohol abuse is a particularly disruptive assumption. In this community many have fought and won the battle against alcohol, and to focus on issues of substance abuse at the outset of a healthcare interaction introduced an element of shame, which creates an uneven power differential in further communication.

Findings were consistent with the literature review, noting indigenous perceptions of stigmatization and communication breakdown, leading to mistrust and unwillingness to access the health system (Eley, Young, Hunter, Baker, Hunter, & Hannah, 2007; Thomas, Benjamin, Almirio, & Lathan, 2006; Williams & Mohammed, 2009). Moreover, studies revealed the reluctance of indigenous to engage with mental healthcare and the strong sense of stigma attached to these services (Hunter, 2002; Eley, Young, Hunter, Baker, Hunter, & Hannah, 2007). However, these articles were not consistent with the

interviews in this study. Many participants were willing to discuss positive experiences with counseling. Reasons for lack of engagement with a therapist were not described as the stigma of mental health disorder, but rather the lack of professional counselors who respected confidentiality issues, particularly notable on-reservation. Whether acceptance of mental healthcare is representative of other communities, or is related to the progress tribal leadership has made in improving access and utilization concerns, is beyond the scope of this study, but warrants further attention.

Particularly in the outpost clinic setting, lack of consistent privacy and confidentiality turned many away from obtaining the help they needed either for mental health counseling, or sensitive medical concerns. The literature supports this finding, particularly with marginalized populations or adolescents, with reluctance to present for care in the setting of uncertain confidentiality (Laric, Pitta, & Katsanis, 2009; Lehrer, Pantell, Tebb, & Shafer, 2007).

Specific aim #3.

The third Specific Aim explored the participant's views of rural outpost care to that of urban centers. All participants believed it was essential to have an outpost clinic, with most feeling that the service is inadequate for their needs. Bimonthly physicians, and several outpost RNs who take one- or two-month shifts at a time provide the basis of all community care. This particular community has had the good fortune to have one experienced RN return repeatedly over the years, providing a sense of continuity while developing strong relationships with the community. Nonetheless, remote care for several

hundred people where traumatic injuries from logging, hunting, fishing, and other marine activities are not uncommon, places a heavy burden on the outpost nurses, and there is frequent turnover. Added to this is the limited medical or cross-cultural preparation healthcare staff receives before going to these locations. The harsh realities associated with remote living encountered by providers increases a sense of disconnect or ‘othering’ with the FN community. This finding was consistent with Tarlier, Browne, and Johnson (2007), where the focus essentially remains on acute care issues, with community involvement and education taking a back seat. Interestingly, Watson, Hodson, and Johnson (2002) found that many providers were uncertain how indigenous clients accessed care, while concurrently admitting that cultural barriers impacted the quality of care given. Gaps in the literature exist in comparisons between provider and recipient perception.

Interviews spoke to the devastating impact that poor communication had in the outpost setting, where repeated examples of bleeding, edema, fatigue, or shortness of breath were not quantified and inaccurate assumptions were made. While repeated stories were told of families stepping in and transporting an individual out to an urban center, tragically, accounts where the individual died from a missed diagnosis were not uncommon.

Consistent with the work of Watson, Hodson, and Johnson (2002), receiving care away from home increased stress and anxiety, although primarily because of financial constraints and separation from the extended family. Alternatively, there was a sense that urban centers offer high-quality healthcare for acute needs. Most notable were the

accounts following cardiac surgery. Participants revealed excellent knowledge regarding lifestyle modifications such as diet and exercise after returning from these episodes. In fact, several were so empowered that they shared the importance of disseminating that knowledge to others in the community. This indicates successful communication and education techniques on the part of these BC centers.

Lack of follow through with urban medical centers or specialists revolved around several factors. The sheer economics of travel and accommodations while away, the logistics of separation from family and responsibilities, or frustration with specialists who either do not offer, or do not successfully communicate an integrated plan of care. Finding an appointment cancelled after days of hard travel to an urban specialist, or inability to obtain a pharmaceutical treatment readily available to the non-indigenous, amplified remnants of a colonial past and the difficulties of providing an equitable healthcare product.

Specific aim #4.

The fourth Specific Aim spoke to whether the level of engagement by FN members was affected by the provider's cultural awareness. This question was deeply embedded within all the responses. Those who expressed satisfaction with care were those fortunate enough to have found a provider with cultural sensitivity, with a willingness to take the time to explain things, engaging each individual in their own care plan. For those who expressed dissatisfaction, at the root of each story was lack of respect, poor communication, a paternalistic power-over-style of practice, or a sense of stigmatization.

Notable in these accounts, it was not always the provider, but ancillary staff members such as receptionists, back office assistants, or ER nurses who caused discomfort with the process.

There is no lack of articles concerning culturally competent healthcare. More recent findings encourage the development of relationship rather than reliance on rote scripts based on racial affiliation (Jirwe, Gerrish, Keeney, & Emami, 2009; Sims, 2010; Vogler, Altmann, & Zoucha, 2010). The desire for relationship with strong communication held true in this study. Responses to healthcare were framed by the experiential, sociopolitical, and historical realities that First Nation people contend with, and without knowledge of these contexts, cultural competence on the part of the provider is unlikely. Armed with this knowledge however, providers expressed awareness of the implications foundational to a disease process, and thus were able to sensitively offer alternatives. Ngo-Metzger, Telfair, Sorkin, Weidmer, Weech-Maldonado, Hurtado, and Hays (2006) provided an excellent paper for healthcare workers on developing cultural competence from the patient's perspective. They consider five domains with implications for tracks of provider/administration and applied research. The domains included:

- 1) patient/provider communication,
- 2) respect for patient preferences and shared decision-making,
- 3) experiences leading to trust or distrust,
- 4) experiences of discrimination, and
- 5) linguistic competency (p. i).

Further research into these domains would provide rich data for healthcare delivery.

Specific aim #5.

The fifth and final Specific Aim explored the use of traditional medicine. Struthers and Eschiti (2004) noted that Native Americans used both traditional and Western medicine concurrently for balance and harmony while being treated for cancer. This project was not consistent with those findings, most significantly because very few use traditional medicine any longer. Participants spoke openly about several of the medicinals used, including where they used to be found, how to prepare the tincture or tea, and directions for use. Yet all stated that within their communities they did not know of anyone still using them. Whether this finding would be consistent for other communities along the BC coast is unclear. Despite the fact that no one currently used traditional medicine, every participant spoke of these cures with a deep-seated belief in their efficacy, either from personal experience or observance of family members. There was a sense of loss that accompanied this lack of use, and comments by several indicated they believed the knowledge to be dissipating. Causes for these losses were described as loss of knowledge due to removal from original tribal land, because of residential school and inability to learn important values from the elders, or relocation away from original reservation to other areas for work or marriage.

Mulaudzi and Makhubela-Nkondo (2006) reported disconnects in communication when indigenous people used traditional medicine as well as those remedies prescribed by Western providers, suggesting a reluctance to ask, or tell about alternative therapies. These findings were echoed, as participants told of physicians who directed discontinuation all traditional medicines, without the courtesy (or curiosity) of what a

person was on, or why. This directive so aptly depicts blatant cultural ignorance and disrespect of indigenous ways of knowing.

Cultural Nuances

The cultural nuances are subtle yet significant, and should be no surprise to any caregiver. First Nation culture is formal and based on respect. One of the most obvious dissimilarities affecting the healthcare setting is the vast differences in communication styles. Conversations are not hurried, much is nonverbal, and individuals are content to simply spend time in each other's company — words alone are not of primary importance. It is clear both from the accounts of positive experiences in culturally sensitive First Nation centers, as well as the negative accounts in mainstream medical clinics, that cultural safety as defined by Ramsden, (NCNZ, 2005) would be a valuable tool for healthcare, but is being inconsistently used.

For healthcare providers, multicultural sensitivity has been a buzz-phrase for decades. The reality is, however, that we have a long way to go towards improving techniques of inter-cultural relations. Overlapping these issues are the components of colonialism and socioeconomics — issues that providers must be familiar with in order to walk in both worlds. Awareness of the political issues specific to regions a provider serves, the realities of what these tribes have undergone and may still be experiencing, and typical styles of communication unique to these groups, both verbal and nonverbal, is a requisite for any competent provider.

These interviews revealed that the most important factor is to show a willingness to listen and be respectful. Recognize that, for many, use of humor is often a means to cover underlying fear, grief, or anger. Mistakes in inter-cultural communication are acceptable, even experienced providers continue to make them. What matters is that interactions are conducted with respect for the totality of *who* the person is, and a willingness to delve below surface appearances. In First Nation culture, this means respect not only for the patient, but for the extended family relationships and the traditions that shape them — past and present.

Progress along the path

In *Progress Along the Path*, it was exciting to see that many of those interviewed were becoming increasingly bicultural and comfortable advocating for self and family members. Several had discussed the long road they and family had taken in counseling and healing to overcome past trauma, and were ready to approach life from a proactive stance. Many spoke of the importance they placed on improving health conditions for the community as a whole, both on- and off-reserve. I was impressed that during interviews and time spent together, almost all shared a deep commitment to improving quality of healthcare. This holistic vision included attention to living conditions, improved economic sustainability, improved access to healthy nutritional choices, culturally sensitive training on how to make those choices, and of course, improved access to trusted providers, where it would be safe to return for integrative care.

Implications for Healthcare – Suggestions by Participants

The interviews provided findings with broad implications. Exploring the findings related to healthcare for remotely situated First Nation communities demands branching into three themes: a) Healthcare delivery on-reservation, b) Healthcare delivery off-reservation, which includes the rural communities that provide support and supplies to the reservations, and c) Healthcare providers, which includes education, training, and discussion of alternative models of care delivery. Many of the following alternatives offered are direct suggestions from participants, and it is hoped that the band will refine, develop, and control these concepts through the use of community-based participatory research.

First Nation Communities on Isolated Reservations.

Current shortages of healthcare providers at every level simply amplify the significant challenges in staffing remote outpost clinics. The following suggestions were given:

- 1) Participants repeatedly voiced frustration with the challenge of presenting to a provider only accessible by boat and believed that a daily clinic on the reservation that would limit undue travel and hardship to community members, and better serve the community.
- 2) The addition of nurse practitioners or physician assistants to manage acute and chronic care needs, perhaps shared between several communities, to complement and support the outpost RNs and physicians.

- 3) In remote locations, the phone and Internet services are not always consistent, however, when available, the use of telecommunications for clinic specialties could be used. This would not only include specialty medical consults for RN/NP/ PA, but for community health representatives in order to clarify appropriate triage and transfers, and provision of a higher-level of care within the community.
- 4) Community members trained as First Responders/EMTs, for additional support during any traumatic or acute event, and to provide telephone triage and stabilization for after-hour emergencies. Ongoing refresher classes for those already fulfilling these roles.
- 5) Separation of the CHR position into clerical and clinical positions.

First Nation Communities Off-Reservation.

For the First Nation individuals who have chosen to live off-reservation, multiple needs exist. While access to healthcare services is increased, many suffer a higher degree of stress away from extended family units, and confront a higher degree of stigmatization living directly within the *whitestream*. An excellent First Nation drop-in center exists in the small, coastal community that serves as a source of healthcare, shopping, and entertainment, where a number of participants were interviewed. This center offers a wide variety of programs for all ages, and is very well-attended. A physician comes once a week for those who wish to make an appointment, and he is highly respected and trusted in the community. Many of the people I spoke to shared how he had changed their lives, by taking the time to really explain what was going on with their health in a way that

made sense. Based on interview findings as well as directly expressed wishes, the following are suggestions for strengthening off-reservation healthcare:

- 1) Full service medical and dental clinics offered through the First Nation Centers, staffed as much as possible by First Nation individuals, who would be responsible for training all non-indigenous providers in cultural sensitivity.
- 2) First Nation liaisons in each hospital and clinic. Currently there are liaisons at most hospitals, yet consistent throughout the interviews was that only a few people knew of the local programs. Those who knew of the liaisons, had used the service extensively and quite successfully. Participants suggested dissemination of the role and availability of this service, and felt this would go far in decreasing fear associated with a family member being hospitalized.
- 3) A liaison program staffed by First Nation people in the medical clinic setting. Several of the elders mentioned that going to a physician was not so frightening if they were greeted with a “Hi auntie,” and made to feel welcome. As the counselors shared, it can be intimidating to speak with authority figures. Having a clinical advocate who would be able to clarify during an appointment and assure that questions were adequately answered and understood, would greatly improve overall health outcomes.
- 4) Workshops: For First Nation members who live both on- and off-reserve, education opportunities are often offered in a workshop format, and

typically they are well-attended. Multiple responses indicated a reluctance to question the provider, and yet those families who either questioned a decision or took matters into their own hands voiced successful outcomes and a sense of empowerment. Workshops on advocacy for self and for family members through role-playing, and on navigating a medical encounter assertively would be invaluable toward self-empowerment and a sense of control over any given medical condition. Other workshops that participants felt would be helpful were a series on parenting, managing finances, and most importantly, constructive ways of dealing with grief and loss.

Healthcare Providers.

Each of the interviews given by the registered nurse, physician, and counselors recognized the lack of culturally sensitive training that providers receive, and the vital importance this has in delivery of effective healthcare. The physician stated, “I did four years of under-graduate, four years of medical school, and two years of residency, and we spent two hours on aboriginal issues.” The providers interviewed felt that it is impossible to deliver appropriate medical care without a thorough knowledge of the history of the people one serves.

While specifics change from region to region, there is much that the indigenous tribes have in common. A curriculum that speaks to indigenous politics, past and present would illuminate issues germane to communication and interaction styles within the healthcare encounter. This curriculum would be extremely important not only for

providers at all levels, from nurses to physicians, but for office and hospital support staff as well, particularly for those areas with a large aboriginal population.

The literature review revealed a few universities that are working hard to involve local tribal elders and spokespersons to teach and develop relationships with new nurses (Arnold, Appleby, & Heaton, 2008; Bindler, Allen, & Paul, 2004; Moss, Tibbetts, Henly, Dahlen, Patchell, & Struthers, 2005). This is an excellent start, yet it appeared that there was minimal involvement by the student body as a whole, and one might assume that those who do not enroll may be in greatest need of the information.

One solution to the challenge of apprehending indigenous history, and subsequent unfolding within contemporary inter-cultural interactions might be to create a documentary, providing a platform for indigenous to share experiences. Elders could tell their stories of residential school and reservation relocations, and describe how this impacts current relationships with the non-indigenous. Younger generations could then share the effect this has had on their lives, as well as the challenges faced in a mandatory bicultural world. The film could follow several First Nation individuals of varying ages through a clinic or ER visit and highlight some of the differences in communication styles, being alert to phrases or actions that may trigger responses. A short segment where the individuals share their feelings after the medical encounter may pinpoint areas for improvement and further education.

Nationally oriented, the film could then be used as a formal entry point of discussion regionally, where part two of the video would then be created to be geographically specific. Surrounding bands could comment on whether the video addressed concerns

adequately, share additional stories to fill out the picture, and clarify history and communication styles unique to the local tribes. These videos could be useful not only for educating new providers, but as cross-cultural in-services for hospitals and clinics that provide care to indigenous people.

Further implications include the requirement of impeccable professionalism and confidentiality. Repeatedly, people commented that within minutes of having shared personal history with a provider, this information was distributed throughout the community. This was particularly an issue on-reservation, where extended family relationships are confusing for outsiders to navigate, and where 'need-to-know' is often confused with 'right-to-know.' Trust is a delicate balance at best, and dissemination of personal information will end a relationship at the outset, leaving the provider considered by the entire community as untrustworthy.

Obvious through every story and account offered was the lack of continuity and follow-through between providers, often with wide differences in approach to chronic diseases. This led time and again to mistrust of the system as a whole, leaving many with a sense that the provider did not really know what he or she was doing. Inconsistency was compounded by individuals reporting to the ER or urgent care rather than consistent follow-through with a primary care provider. Yet the majority of those I spoke to voiced the desire to have a strong relationship with a provider. Certainly those who had discovered this relationship were very proud of it, and repeatedly told stories of how this provider had assisted them in the past, and how well they were doing personally because of it.

First Nation providers are significantly under-represented in the healthcare fields. Tribal councils do offer scholarships and tuition assistance for members to obtain training, nonetheless, many of those who are best equipped to further their education are also necessary to the stability of their family structures at home. This places a significant emotional and physical burden on these individuals.

Institutional refusal to change plays an integral part in the cumulative harms in civilized oppression (Harvey, 1999), and healthcare education (nursing, medical, and dental) is challenged to interrogate programs and ethically question methods which favor the *whitestream*. Responsibility for creative alternatives must lie with educational institutions. There are multiple methods available through technology and telecommunications that should make completion of higher education programs possible, even for those challenged by leaving the reservation for any length of time. On-line academic formats, using community school teachers as tutors and proctors, along with outpost physicians and nurses for preceptorship, would allow for the majority of classes to be completed, punctuated by several weeks each semester in order to obtain breadth of experience.

Methodologic Implications

Choosing a qualitative framework was consistent with the work of Halabi (2005), where the importance of allowing voices to be heard opened bidirectional conversation about issues that otherwise may not have been uncovered. Individuals clearly asserted their own voices by adding deeper content to a story outside of the formal process,

including family and friends during the interview, or offering personal accounts only within an informal setting. On reflection, these assertions were a subtle disagreement with my methodologic choices such as the more uncomfortable private, taped interviews and written informed consent as opposed to spontaneous community interaction and ability to accept a verbal consent.

In any qualitative study there cannot help but be an agenda, on the part of both the investigator(s), as well as those who participate. Having spent time over the years in these and other First Nation communities, I was well aware of the dramatic deficits that many endure at every level, politically, socioeconomically, and in healthcare delivery. Both as an outsider and as a nurse practitioner, I felt that many participants offered what they thought I wanted to hear. There was a sense that responses may have been fuller or more specific if given directly to the community research partners, as First Nation hospitality and graciousness may have played a part in protecting me as a known part of the medical establishment. Others offered interviews that were decidedly political within the current issues of treaty talks and tribally-controlled services and funds.

Throughout data collection and subsequent analytic iterations, it became apparent that certain applications of methodologic rigor held greater congruency with the purpose and methods of the study. Critical ethnography requires a fresh look at how we assign the over-arching attributes of ethics and trustworthiness (Lincoln & Guba, 1985), and numerous implications for methodology arose. I will discuss strengths and limitations of the study along with the methodology, as they are deeply intertwined.

Ethics.

The ethics of a research study include informed consent, privacy and confidentiality, risks and benefits, and researcher bias, and each are paramount to creating and maintaining relationships. During the study, privacy and confidentiality were the hot topics. These had frequently been disregarded in healthcare encounters, thus the attentiveness to these issues served to foster trust and increase the depth of interviews. Risks and benefits were reviewed both verbally and in the written informed consent, however participants in this study appeared uninterested in these points, and as one elder stated “We all have our stories to tell, and want to be heard.” Not one interview was conducted alone, and having at least one family member or trusted elder present provided a less threatening venue.

Being known in the community as a nurse practitioner served to both confuse and assist in the data collection. Initially careful not to insult my sensibilities as a part of the medical establishment, interviews were ‘polite.’ However, as energy grew around the project, and recognizing this as an opportunity to share what was and was not working in healthcare, experiences came readily, both positive and negative, as well as multiple suggestions on what each would like to see improved. Sitting in a circle of women in someone’s living room, or on a crowded skiff on the way to a picnic served as opportunities for the stories and laughter that took us well beyond the formal taped interviews. Throughout my time in both communities, as people discovered I was a nurse practitioner, there would be many questions regarding diagnoses. What did this mean? What could have been done differently? Are there other medicines that would work?

What should we do if ...? The list went on. From these questions two things were clear — satisfying answers were not being offered, and people were reluctant to ask for clarification from the provider. Multiple community members used my presence as a way to learn more about a diagnosis, or discuss the pros and cons of an ongoing treatment plan, and through these questions, revealed a need to have a trusted advocate in place.

A serious limitation of the study was the issue of written consent. Important to the validity of the interviews, and essential to the relationship, was the return for member-checking and verification of meaning. Thus a record of participants had to be maintained, which required written consent, despite the final document being completely anonymous as to location and tribal affiliation. As mentioned before, in small communities, and despite removing all identifiers, anonymity is not possible, yet one can effectively honor privacy.

Formal written documents requiring signatures in this cultural setting however, created a serious impediment to trust and the developing relationship. Many community members sought me out away from the formal interview process in order to share their experiences. Others gave a ‘polite’ formal version, and then continued to add to this during informal activities. Personally, requesting a signature on a three-page (simplified) consent form felt hierarchal, minimizing the verbal consent received, and in a sense, inferring that ‘their words were not enough.’

Without a doubt research must be ethical. At the same time it is imperative that research be moral. As a post-colonial outsider, working with marginalized communities

traditionally oral in culture, the written consent was not appropriate. Methods based in respect do include:

- 1) Getting permission from the chief after a detailed description of the purpose and methods of the study,
- 2) Getting agreement to partner in the research by well-respected community elders who have access to each anonymous transcript, and participate in analysis,
- 3) Having a verbal discussion of purpose and having permission granted before obtaining a recording of each formal interview, and
- 4) Returning to each member with a written copy or summary of the transcript, while again receiving verbal permission and clarifying allowable segments, as well as those to be removed.
- 5) Getting permission and agreement from both community partners prior to any publication of data or analysis.

It is time that we examine methodologies for the particulars of those we work with. For research to be justice-based, it is especially critical that we take into account the specific needs of communities or people groups, and not lose sight of these issues beneath pages of regulations.

Rigor.

The model from chapter three (Figure 10) provided a platform for active analytic stance and ability to determine sampling adequacy, which lead to reliability and validity. Iterations provided a vehicle to move from an emotional to structured perspective in analyses.

Lincoln and Guba (1985) define trustworthiness as the umbrella over credibility, dependability, confirmability, and transferability. Morse (2002) included investigator responsiveness as an integral piece of trustworthiness. Throughout data collection, any lapse in ethics or trustworthiness would have seriously impacted further interviews and brought the study to an immediate halt. More importantly, lapses in analysis influence the future quality of relationship and community partner responsiveness. This is where credibility is such an important factor.

Credibility is difficult to assure in terms of recognizing whether there is distortion of the data, particularly when faced with being an outsider and a relatively short period of time within the community. It can be expected, and this study was no exception, that individuals will offer accounts based on contextual circumstances. In the face of ongoing treaty topics and council elections, formal interviews had a decidedly political flavor. However, with sampling between two communities representing several tribes, sampling was determined to be adequate, both through the formal interviews as well as the rich informal accounts, integral to ethnographic inquiry, which verified saturation.

Dependability is determined in part by the ability to accurately judge both the strengths and limitations of a study. Limitations of the study included the relatively short period of time available for relationship-building. Involvement in communities such as these is measured in years, not weeks, and it cannot help but have an impact on disclosure. Other limiting factors included the time of the year chosen, as early summer is an extremely busy time with the first fish runs. Political preparations and elections during this same period diverted focus, and may have impacted the direction certain interviews took.

Strengths of the study included the use of open-ended interviews that provided a wide platform for discourse. Rich data were collected that expanded far beyond the specific aims of the study, and would have been missed with a formalized survey technique. Family connections through adoption provided a trusted entrée for me to meet, and stay with community members, which would have been unavailable in other settings. Additionally, the community research partners who were involved in reading and critique of both interviews and analyses provided cultural validity. Interviews with the family counselors, registered nurse, and physician confirmed reliability and consistency through triangulation of the data, as did the literature review. An important strength of this design, which impacted the willingness of others to share experiences, was the return to source for verification of meaning.

Consistent with the literature and throughout the analysis, it was determined that transferability is not an accurate measure in critical ethnography because of the nonstatic

and ever-changing political and geographic realities of marginalized communities.

Critical comparison with extant literature provides potential generalizability, but these attributes must be loosely held at best.

We are of an age in qualitative research, and specifically in critical ethnography, where the standard methodologies are no longer adequate. This does not mean that attributes such as credibility and dependability should be discarded, nor does it lessen the stance on ethics. On the contrary, studies with marginalized populations require a much closer inspection of our ethics, biases and purposes. Lincoln (2002), proposes that only the communities in question — those who are the focus of the research — will be the arbitrators of quality.

Fine, Weis, Weseen, and Wong (2003) discussed the social responsibilities for those who work with marginalized populations, and listed 10 questions that each investigator must reflect (listed in Chapter three). Each question is essential for any critical ethnography, and must at the very least be incorporated into research memos or journals. However, several are particularly resonant for this study:

- 1) The connection of individual “voices” and “stories” to the historic, structural, and economic relations in which they are situated,
- 2) Participant review of material and analyses complete with agreement, dissent, or challenges,
- 3) Analysis offers an alternative to the “common-sense” or dominant discourse, and
- 4) How far do I go in theorizing the words of informants?

I have held myself responsible to address each of the 10 questions these authors posited, and this study has particularly adhered to the first three points listed above. The

fourth — can I theorize the words of informants? — I do not believe so. I do not believe that to be the right of an outsider. This study can provide a composite of stories, expose issues, and reveal themes. The next step belongs to those who have told the stories, and who choose to embrace what has emerged.

Along with the questions posed by Fine, Weis, Weseen, and Wong (2003), Lincoln's (2002) criteria for qualitative research holds merit, particularly as these relate to empowered voice, critical subjectivity with a negotiated interpretation and determination of future action, reciprocity, and sacredness. Yet each of these is ethereal and difficult to substantiate concretely. There is a middle ground here — a place where these questions of consciousness and relatedness encompass trustworthiness, and conform to the traditional methodology of credibility, dependability and transferability. This is the future work, and perhaps a place where outsiders can assist in the development of new theory and methodology.

Implications for Future Investigations

Indications for further investigation are unlimited, but in keeping with this study, would focus on documenting the development of community-based participatory-action research (CBPR) and associated programs. The literature revealed CBPR successfully used by a number of tribes in the United States (Andersen, Belcourt, & Langwell, 2005; Chino & DeBruyn, 2006; Holkup, Tripp-Reimer, Salois, & Weinert, 2004; Schinke, et al., 2008), and this methodology, developed and controlled by the community, would be quite timely in view of current treaty negotiations and uncertainty of future healthcare

delivery mechanisms. Through these interviews, interest was generated, commitments received from a number of band members to tackle specific issues around local health-care, and this project is simply the beginning in what is expected to be a vital and ongoing initiative.

Additional studies, again based on comments and suggestions received during the interviews would include that of exploring statistics on quality of life and health indicators for First Nation individuals who avail themselves of: a) physicians at the local FN Centers versus intermittent use of the ER, which may reveal stronger incentives for integrative care programs, b) telemedicine consults and triage with local outpost nurses and other healthcare teams, c) dynamic workshops on grief and loss, with cognitive behavioral training and other mental health modalities, and d) sustainable permaculture gardening projects run by the communities.

Summary

Occasionally, one gets the opportunity to step beyond one's border ... to step if only for a brief moment in time, into another world. This past summer was such an opportunity, where the traditions of song, dance and feasting are still vitally important ... where seasons are celebrated by sharing the harvests ... where survival and surmounting obstacles are worthy of celebrations of life ... where not only parents stand for those joining in marriage, but the entire extended family. Commitments span across clans and generations — past, present, and future. This is a world those of the *whitestream* seldom are given opportunity to witness. We can, however, honor it.

Dominant throughout the findings was the fact that experiences of healthcare are not isolated to the medical condition, but integrally webbed within the sociopolitical situation. While the Specific Aims looked at the barriers to healthcare through the medical experiences, findings ranged far beyond these aims, and voiced perceptions of racial stigmatization, complacency and even conspiracy. Fine, Weis, Weseen, and Wong (2003) challenged investigators to have social responsibility, asking a series of questions to verify accountability to the data. Situating the “voices” and “stories” of participants within the historic, structural, and economic relations clearly demands a more comprehensive model of healthcare delivery in which there is adequate training of providers in the historical and political realities of those they serve. In order to achieve successful health and wellbeing, a thorough knowledge not only of past, but current politics and ongoing paternalism is necessary. Any healthcare model must incorporate the profound grief around all of these issues.

The dominant discourse in healthcare to the indigenous has been overtly limited by lack of providers and funds. The subtle limitations, such as not addressing cultural generalizations and assumptions, or the recognition of deep socioeconomic stressors has undermined healthcare delivery at every level. Consistent with Williams, Neighbors, and Jackson (2003/2008), the discriminatory stress and blocked opportunities were a part of every extended-family story at some level. Cloaking social justice beneath the mantle of chronic disease obscures *whitestream* responsibility and shifts the blame to the oppressed. Noncompliance with chronic syndromes such as obesity, diabetes, and heart disease is

considered the real culprit, while the sociopolitical root causes go uncorrected, and often unrecognized.

There are no easy answers, nor is any one party entirely to blame. As Facione and Facione (2007) found, perceptions of prejudice are directly related to poorer outcomes in preventable health behaviors. Thus programs for healthcare advocates, workshops, and improved case management are short-term alternatives that may alleviate the symptoms, but not touch the root of the problem. We will not accomplish long-term solutions, however, without addressing the sociopolitical disparities that currently exist.

Dynamically growing, both in population numbers as well as self-empowerment, there are those who are hungry for change and ready to be part of the creation of a more healthy community. There are many positive initiatives being accomplished on the part of band council as well as the healthcare team, yet from these interviews, there is such a deficit, that positive changes are like small ripples in a pond. As a critical ethnographer, I attempted to highlight issues of injustice and need. In a complex and fluid political context with multiple agendas, mining the depth of inequalities and issues of justice will take decades, and this study simply scratches the surface. The priority, and my personal agenda in this project, was to develop relationships, with the hope of stimulating interest and energy around community-based participatory research.

This study was conducted as a bridge — to build relationships and trust and to give voice where for too long there has been silence. This study is not the solution, nor can I as an outsider create it. The solution must come from First Nation community

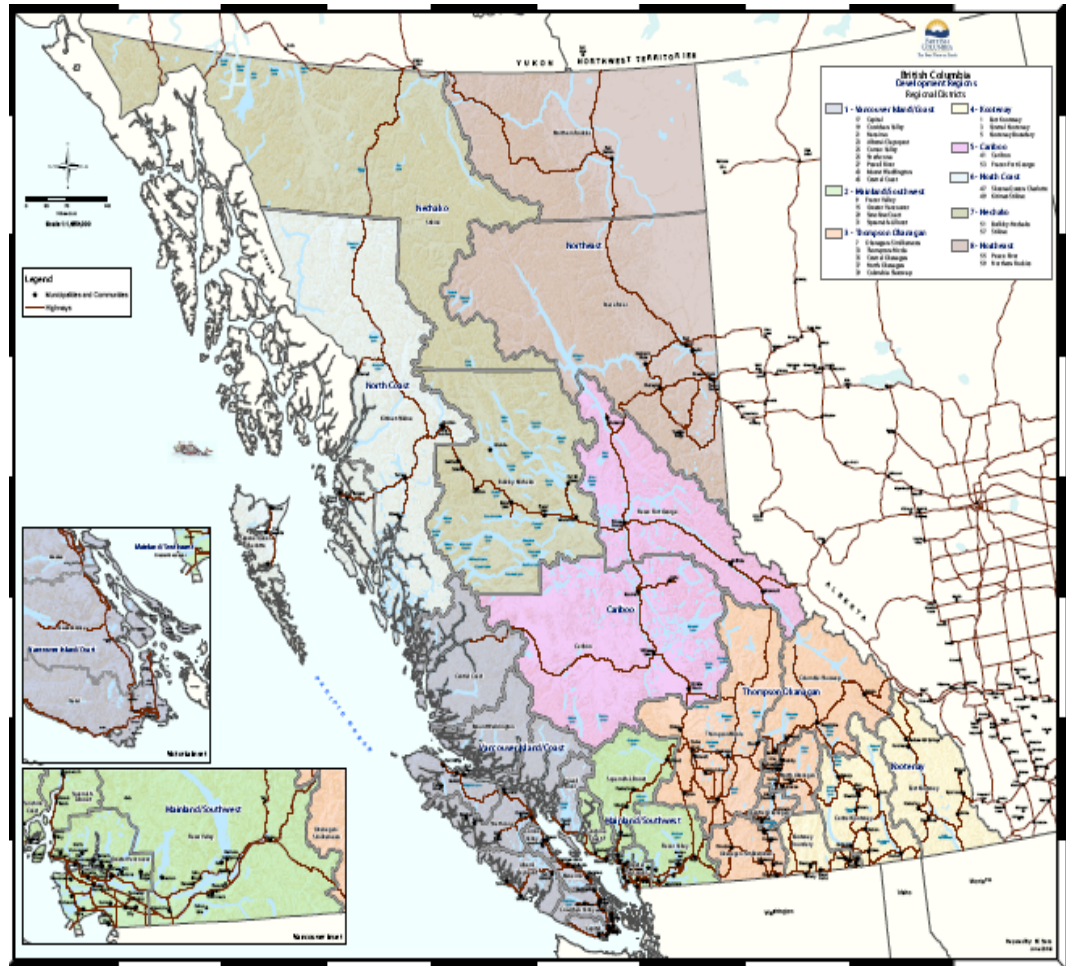
members, perhaps in concert with committed outsiders, but controlled from within. The first links in this chain are the community research partners, and from there the band and tribal councils. Further investigations by First Nation individuals as to the healthcare priorities communities consider essential will be important.

To claim one's voice is to claim one's power. The stories and experiences articulated in these interviews is one means for these communities to claim voice, and is only the beginning. To own the data and be willing to act on it thus creating new methods of knowing and interacting is another means of claiming not only voice, but power. This entails both a challenge and a commitment, from those involved in healthcare delivery as well as the First Nation communities who will step up to claim an improved quality of care. It starts here ...



Figure 19. Partnership. Lottis, 2010.

APPENDIX A



APPENDIX B

Text of Prime Minister Harper's apology

Wednesday, June 11, 2008

The prepared text of the apology Prime Minister Stephen Harper delivered in the House of Commons on Wednesday. Paragraphs in parentheses were spoken in French:

Mr. Speaker, I stand before you today to offer an apology to former students of Indian residential schools.

The treatment of children in Indian residential schools is a sad chapter in our history.

(For over a century the residential schools separated over 150,000 native children from their families and communities)

In the 1870's, the federal government, partly in order to meet its obligation to educate aboriginal children, began to play a role in the development and administration of these schools.

Two primary objectives of the residential schools system were to remove and isolate children from the influence of their homes, families, traditions and cultures, and to assimilate them into the dominant culture.

These objectives were based on the assumption aboriginal cultures and spiritual beliefs were inferior and unequal.

Indeed, some sought, as it was infamously said, "to kill the Indian in the child."

Today, we recognize that this policy of assimilation was wrong, has caused great harm, and has no place in our country.

132 schools financed by the federal government were located in all provinces and territories with the exception of Newfoundland, New Brunswick and PEI.

Most schools were operated as "joint ventures" with Anglican, Catholic, Presbyterian or United Churches.

The government of Canada built an educational system in which very young children were often forcibly removed from their homes, often taken far from their communities.

Many were inadequately fed, clothed and housed.

All were deprived of the care and nurturing of their parents, grandparents and communities.

First Nations, Inuit and Metis languages and cultural practices were prohibited in these schools.

Tragically, some of these children died while attending residential schools and others never returned home.

The government now recognizes that the consequences of the Indian residential schools policy were profoundly negative and that this policy has had a lasting and damaging impact on aboriginal culture, heritage and language.

While some former students have spoken positively about their experiences at residential

schools, these stories are far overshadowed by tragic accounts of the emotional, physical and sexual abuse and neglect of helpless children, and their separation from powerless families and communities.

The legacy of Indian residential schools has contributed to social problems that continue to exist in many communities today.

It has taken extraordinary courage for the thousands of survivors that have come forward to speak publicly about the abuse they suffered.

It is a testament to their resilience as individuals and to the strength of their cultures.

Regrettably, many former students are not with us today and died never having received a full apology from the government of Canada.

The government recognizes that the absence of an apology has been an impediment to healing and reconciliation.

Therefore, on behalf of the government of Canada and all Canadians, I stand before you, in this chamber so central to our life as a country, to apologize to aboriginal peoples for Canada's role in the Indian residential schools system.

To the approximately 80,000 living former students, and all family members and communities, the government of Canada now recognizes that it was wrong to forcibly remove children from their homes and we apologize for having done this.

We now recognize that it was wrong to separate children from rich and vibrant cultures and traditions, that it created a void in many lives and communities, and we apologize for having done this.

We now recognize that, in separating children from their families, we undermined the ability of many to adequately parent their own children and sowed the seeds for generations to follow, and we apologize for having done this.

We now recognize that, far too often, these institutions gave rise to abuse or neglect and were inadequately controlled, and we apologize for failing to protect you.

Not only did you suffer these abuses as children, but as you became parents, you were powerless to protect your own children from suffering the same experience, and for this we are sorry.

The burden of this experience has been on your shoulders for far too long.

The burden is properly ours as a government, and as a country.

There is no place in Canada for the attitudes that inspired the Indian residential schools system to ever again prevail.

You have been working on recovering from this experience for a long time and in a very real sense, we are now joining you on this journey.

The government of Canada sincerely apologizes and asks the forgiveness of the aboriginal peoples of this country for failing them so profoundly.

(Nous le regrettons.)

We are sorry.

In moving towards healing, reconciliation and resolution of the sad legacy of Indian residential schools, implementation of the Indian residential schools settlement agreement began on September 19, 2007.

Years of work by survivors, communities, and aboriginal organizations culminated in an agreement that gives us a new beginning and an opportunity to move forward together in partnership.

A cornerstone of the settlement agreement is the Indian residential schools truth and reconciliation commission.

This commission presents a unique opportunity to educate all Canadians on the Indian residential schools system.

It will be a positive step in forging a new relationship between aboriginal peoples and other Canadians, a relationship based on the knowledge of our shared history, a respect for each other and a desire to move forward together with a renewed understanding that strong families, strong communities and vibrant cultures and traditions will contribute to a stronger Canada for all of us.

APPENDIX C

Interview Demographics, Question(s) with potential probes

1. Can you tell me how old you are?
2. How many years have you lived in -**-?
3. Can you tell me what you consider your health like now?
4. Can you tell me about an experience you had while receiving healthcare – either in a hospital or clinic, or with a doctor or nurse?
 - a. Were there certain things done or said that made this experience harder?
 - b. Was there anything in that experience that helped make it easier or better?
5. Do you ever using traditional healing methods to care for yourself (ie. Herbs, dances etc)? If so, do your healthcare providers ever ask you about these? Do you ever offer that information?
6. Have you ever had to receive care in (-**- or -**-) large town or city, rather than here in -**-? What was that experience like for you?
7. Do you have family members receiving care in (-**- or -**-) large town or city? What's that like?
8. Is there anything else you'd like to tell me about or add today?

** Villages and small town hospital/tertiary care sites will change based on community location.

Group interviews will not ask for demographic information, but will be asked the same questions as for the individual interviews. In addition, in the group interviews, participants will be asked:

What are the hardest or most challenging parts to getting good care?

What are the parts now that work the best?

What do you need?

APPENDIX D

Hi _____,

It was great talking with you the other day, and I'm really excited that you're willing to partner in this study. This is something that I've been passionate about for a long time, and I know is close to your heart as well. As we talked about, I'm sending you a follow-up outline of the basics of this study, what I hope to see us work towards, as well as the basic format this would take. As we talked about, I expect these interviews to move toward the following: 1) To empower people to claim control over elements of healthcare considered essential to their wellbeing, and (2) To impact policies and delivery mechanism of the healthcare system itself.

Hopefully this is a format you can use to share with community members. Let me know if you have anything to add or change – again, this is about what you want or need to see happen in terms of healthcare, and while I'm instigating it for my doctoral dissertation, it's really about all of you.

PURPOSE OF STUDY:

We are asking people to tell us about experiences you've had with getting healthcare. As we hear your stories, we can start to see patterns that repeat. If we can see things that work and that each of us want, and hear about things that don't work and have made it harder, maybe we can think of ideas that will let us work towards what we want in a healthcare system. If we can discover ways to provide better care, we can help create new policies for healthcare delivery in our communities, as well as culturally sensitive training for new providers.

PARTICIPATION:

There are a few ways you can help in this project:

Tell your story in an interview which will be taped so that no mistakes are made and we get your words right. Once it's typed up, we will come back and make sure it says exactly what you wanted it to say, and make any changes or add anything you thought about later. If you decide you don't want the story to be used at all, just say so and the tape will be erased and we won't use the story. If you want to use your name you can,

but if you don't want anyone to know you told the story, you can choose another name to be used instead.

We can sit as a group and talk about those things that haven't been working, and those parts that have – and what we would like to see change. No one would have to give their name unless they wanted to.

You could draw, paint, carve, photograph or dance things that show what your health is to you, again you can use your name or not.

If any of you want to help with this, just let me know, or talk to Karen when she gets here this summer.

FOLLOW UP:

After the stories have been told and groups have met, it will take some time to write it out and find the themes. When that's done and before it is completed, we will review the document to make sure it represents our community. We will receive a copy of the final dissertation as well as any further publications based on this project.

APPENDIX E

Purpose of Study and Consent Form

Introduction:

My name is Karen Lottis, and I am a nurse practitioner and co-investigator in a study that is exploring the experiences First Nation people have in getting medical care in remote and rural areas. I would like to talk to you about experiences you have had with your healthcare – for example, either in a hospital or clinic, or with a doctor or nurse. I hope that with the stories people share, we can learn about the things that do work, and start to understand the things that don't work – and maybe think of ways to make the healthcare system work better for you and your families.

What will happen if I decide to participate?

- I would be honored to sit and listen to any experiences you've had. I would like to tape record them so that I get your story right.
- Each interview will take anywhere from 30 to 60 minutes – it's up to you how long it goes.
- After I write out the story you tell, I would like to come back to you in a couple of days so that you can read it, or we can talk about it together and make sure I didn't make any mistakes, and that we got what you want to say down. If you want to add anything or change it, you can. If you decide you don't want me to use it at all, that's ok too.

How will my information be kept private?

- If you want to use your real name when we write about these experiences you can. If you would rather no one know that you told your story, you could pick another name that you would like use instead – or not use any name at all. It's up to you.
- All of the interviews will be kept in a computer that only I can access with a password, and once the study is complete, the recordings will be erased.

_____ I would like to share my healthcare stories, but do not want to use my real name.

_____ I would like to share my healthcare stories, and would like to use my name.

What other choices do I have if I don't want to be interviewed?

- If you are uncomfortable with an individual interview, but would like to talk about your experiences as a group where we don't use anyone's names, but instead we just look for some of the themes in all your stories, that would really help us understand as well.
- If the telling of your story is too hard or uncomfortable, but you want to be a part of this work, taking a photograph, painting a picture, carving or drawing what signifies health to you may touch people where words can't go.

_____ I have created artwork or a photograph, and I give permission to have it photographed or copied, and used in this study.

_____ I do not give permission for it to be used in this study.

What are the risks of being in this study?

Sometimes when we tell about our past experiences, it hurts all over again. If you think that might happen, please invite someone that you trust, like a family member, elder, or _____ (study partner in specific community) to be present during the interview.

What are the benefits from being in this study?

What we hope to find as you share your experiences are patterns in the things that are most important to you, and things that are not working. When we see similar patterns it gives us ideas of how to make new models for clinics and healthcare providers to do a better job. Perhaps as you each share your stories, it will make it clear what are the most important pieces to good healthcare for the whole community, and as a people you can start creating changes that benefit you.

Will I be paid for taking part in this study?

- A gift will be given in respect and thanks for the time you took to share your story.

How can I be sure my stories will be respected?

- _____ and _____ (community partners) have agreed to help read and discuss the main themes of these interviews as cultural experts representing the people of _____. They will make sure that these themes and writings reflect what you and others have said.
- Once the document has been written, but before it gets published, I will bring it back and talk with _____ and _____, as well as any others that would like to be involved, to make sure it honors the needs of this community.
- I look forward to any suggestions or advice they have to make it stronger. Once it is published, I will leave a copy here so that anyone can read it.

Can I change my mind once I start?

- Yes, if at any time during the first interview, when I come back to make sure that we got it down right, or later when the document has been written, you can change your mind and I will take your story out.

CONSENT

You are making a decision whether to participate in this study and have your real name used. Your signature below indicates that you read the information provided (or the information was read to you).

I have had an opportunity to ask questions and all questions have been answered to my satisfaction. By signing this consent form, I agree to participate in this study. A copy of this consent form will be provided to you.

Name	Signature of Adult Subject	Date
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INVESTIGATOR SIGNATURE

I have explained the study and answered all of his/her questions. I believe that he/she understands the information described in this consent form and freely consents to participate.

Name of Investigator

Signature of Investigator

Date

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