DEVELOPING A DIABETES PROGRAM IN A FIRST NATIONS COMMUNITY

By

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In

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We accept this thesis as conforming

to the required standard

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Abstract

This project describes the process of creating understanding between cultures essential to the development of effective health intervention programs, such as those related to diabetes. Current structures and beliefs are explored: political, geographic, organizational, cultural and health-care system-related, including the impact of history on present circumstances. The interwoven nature of Aboriginal health conditions is illustrated by the voices of eleven members of the Haisla First Nation.

Final recommendations attest to the complexity of the jurisdictional and attitudinal conditions in which we as First Nations and non-Aboriginal health-care providers must work. Progressing through the recommendations for any restorative program will begin with our examining our attitudes, clarifying assumptions and building trust. Executive level support must be demonstrated but like the delicate strength of a spider's web, the central local connections will ensure the integrity of the relationships and the sustainability of programs.

Acknowledgements

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Definitions

Aboriginal includes Inuit, Metis, and First Nations peoples. The Department of Indian Affairs also divided First Nations into "Status Indians" and "Non-Status Indians." The absurdity of these latter designations is evident in this explanation by Dupuis (2002): an Indian woman who married a non-Indian was deprived of her Indian status, while this was not the case for her brother who married a non-Indian (pp. 83-84). I will not use these terms.

Reserve refers to the land allocated to the First Nations bands by the federal government for use by Status Indians and their dependents. Kitamaat Village is the main reserve for the Haisla (pronounced hi-sla). First Nations community is a preferred term (K. Patterson, personal communication, September 18, 2003).

Type 2 Diabetes comprises about 90% of the diabetic population in general; First Nations' incidence is no different. Diabetes is a disease that can occur at any age in anyone. The condition arises when the insulin produced by the pancreas ceases entirely, as in the case of Type 1 diabetes, or the cells of the body become insensitive to existing insulin or the insulin produced is inadequate, resulting in Type 2 diabetes. Both result in abnormally high levels of blood glucose (sugar) that, if left untreated, will cause damage initially to the small blood vessels in the eye and the kidney, and numbness in the tips of toes and fingers. Impotence is common, cuts heal poorly, and untreated infections can lead to amputations and kidney failure (Whitney & Rolfes, 1999).

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CHAPTER ONE – STUDY BACKGROUND

Of the approximately 2 million Canadians who are diabetic, an alarming proportion are Aboriginal, with the national age-adjusted prevalence three to five times higher than that of the general population (Canadian Diabetes Association, Clinical Practice Guidelines Expert Committee, 2003). This project explores how a small Haisla First Nations community can access better health care through collaboration with an 18-bed hospital/health centre facility by investigating the following questions:

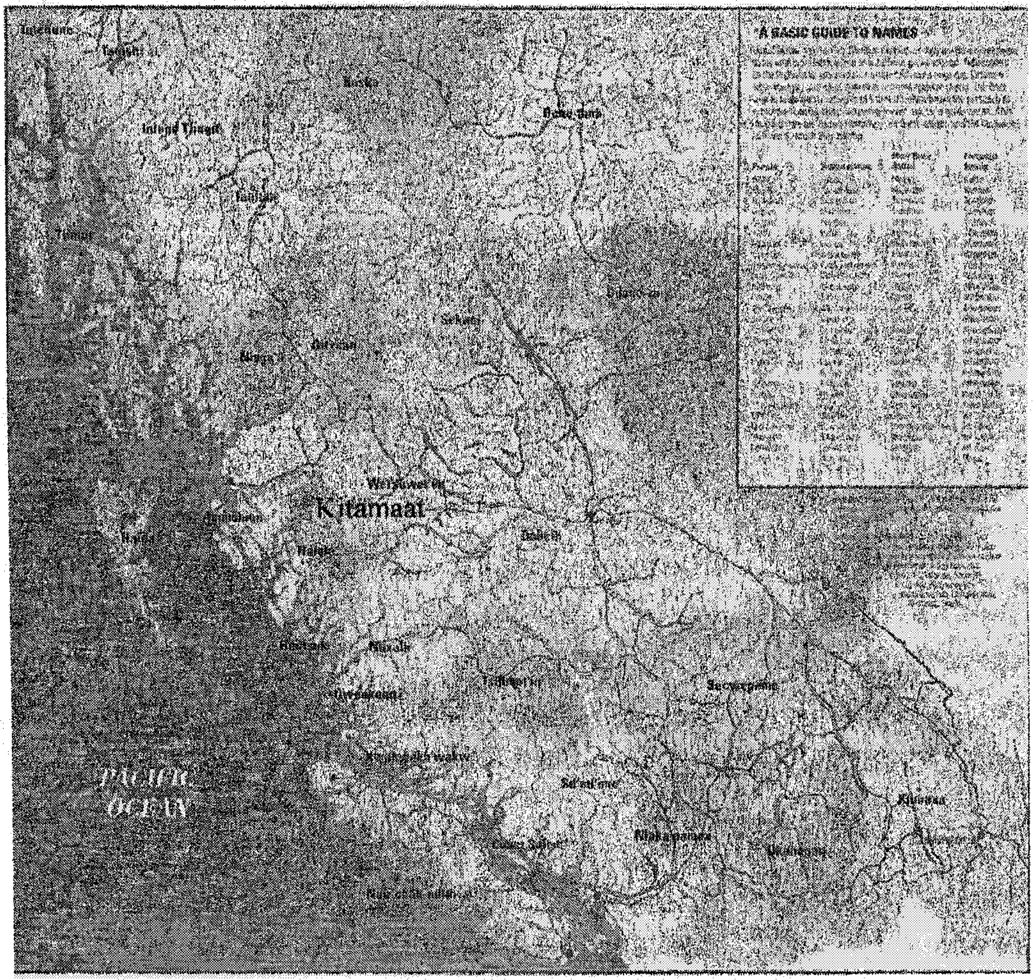
- Given that the Northern Health Authority (NHA) has a specific Aboriginal Health Initiative, how can it best address the needs of the Haisla First Nation, particularly as related to the prevention and treatment of diabetes?
- How do the Haisla define health as it relates to diabetes? What are their beliefs around prevention?
- Are traditional values and practices seen as being important to incorporate into learning sessions, and if so, how might this be done?
- What are the obstacles to accessing comprehensive diabetes treatment?
- From the standpoints of the general Haisla community and the Haisla Health Centre staff, what do they feel would help in the prevention and treatment of diabetes?
- What are the current forms of diabetes education and where do they take place? What multidisciplinary steps are being taken?
- What feedback loop(s) may be required to ensure ongoing assessment and sustainability of the NHA interventions/programs?

Some of these questions are more fully explored than others in this research project because of time constraints; however, my ongoing passion to find solutions remains strong.

The Problem/Opportunity

Kitamaat Village is located on the northwest coast of British Columbia, 14 km from the town of Kitimat, at the end of the Douglas Channel. The following map shows the Haisla territory, encompassing Kitamaat and the Kitimat Valley, in relationship to the other First Nations territories within the boundaries of British Columbia.

Figure 1. Map of First Nations Territories, Haisla Territory (BC Ministry of Education, 2001)



There are approximately 1,050 Haisla First Nation residents, about half living in Kitimat and half in Kitamaat Village (Statistics Canada, 2003). Diabetes is deemed an epidemic among First Nations (Health Canada, 2003a). Kitamaat Village is no different. According to health centre staff, approximately 1 in 10 of the residents have been diagnosed with diabetes, which falls in line with the finding that 1 in 5 patients seen by their doctor will have abnormal glucose readings (K. Lawson, teleconference, February 10, 2004).

Many Haisla have limited access to the diabetes program, lab, and physicians at the Kitimat General Hospital and Health Centre, even though the centre is only a 20-minute drive away. In part, the limited access results from the lack of affordable transportation from the village. No public transportation other than taxi exists and when extended families depend on one wage earner and potentially one driver, the problem of transportation becomes challenging.

The economic status of village residents spans a wide range given large local employers such as Alcan, Eurocan Pulp and Paper, and Methanex, an ammonia-producing plant. Average annual earnings are $42,590 based on 80 employed residents working full-time. However, for the 385 people 15 years of age and over with income from earnings or government transfers, the median annual income is $12,480 as compared with the BC average of $22,095 (Statistics Canada, 2003). Approximately 70 residents are over the age of 65.

In Kitamaat Village, a Licensed Practical Nurse provides the bulk of the diabetes education as Diabetes Co-coordinator, a half-time position, along with doing home support. She works with the Community Health Representative and a recently added Home Support Worker, all supervised by a Registered Nurse (RN). They do not have a comprehensive diabetes education program. The Diabetes Education Program (DEP) in Kitimat comprises a

Certified Diabetes Educator who is an RN, an administrative assistant and a Registered Dietitian, formerly me.

Doctors refer all newly diagnosed patients with diabetes to the DEP for initial teaching and follow-up, on either a group or an individual basis. Attendance by many Haisla at previous education sessions, both in town and in the village, has been poor. Numerous missed appointments by village residents are common when scheduled for individual follow-up with either the nurse or the dietitian. Inadequate follow-up is influenced by little joint programming between the two centres.

First, as a part of its mandate, the Northern Health Authority (NHA), under which the Kitimat General Hospital and Health Centre is included, has developed the *Aboriginal Health Services Plan* (Patterson, 2003). Despite this document being released to the approximately 70 band offices in May 2003, health centre staff learned of it only when I gave them a copy after attending a Primary Health Care training week in September, in Prince George. Apparently, information may be sent to band offices without being passed to the appropriate department. First Nations health care providers are not consistently receiving information from the NHA.

Next, the information being received by the Haisla from all sources regarding diabetes treatment and prevention needed to be assessed. The content would be compared to what they thought they required for managing their diabetes and preventing complications. Finally, the NHA needed to know how best to address the insufficiencies in order to improve Haisla health status.

Specifically, given the existence of a regional *Aboriginal Health Services Plan,* the Hospital DEP needed to align itself with NHA objectives and learn ways to improve its Aboriginal diabetes education. I concur with Boston et al. (1997) that there is a justified uncertainty over spending large amounts of money on programs and services that, while tested and proven in the South with non-Aboriginals, may not be effective or as efficient in the North with First Nations people. The real issues may be misunderstandings due to cultural differences, the influence of geography, or confidentiality concerns.

How can the NHA, given that it has the *Aboriginal Health Services Plan*, best address the needs of the Haisla First Nation, particularly as they relate to the prevention and treatment of diabetes?

Significance of the Problem

According to the Canadian Diabetes Association, Clinical Practice Guidelines Expert Committee (2003), although three to five times more Native Canadians are experiencing diabetes than are the general population, only 1 in 4 can identify the leading causes of diabetes. The guidelines also point out that 80% of people with diabetes will die of heart disease or stroke. Yet, according to Stewart Harris, Chair of the Guidelines Expert Committee and Associate Professor and McWhinney Chair for Family Medicine Studies at the University of Western Ontario (as cited in Canadian Diabetes Association, 2003, October 17),

> We now have solid clinical evidence that it is possible to prevent one of the most common and costly chronic diseases affecting Canadians; Type 2 diabetes and its related complications can be prevented by lifestyle modifications – moderate weight loss and regular exercise – and in some people by the appropriate use of drugs. (para 4)

Harris warned, "But diabetes must be prevented *sooner*, and diagnosed *earlier*. And once diagnosed, all types of diabetes must then be managed *much more aggressively*" (para 5).

Diabetes is a symptom of Aboriginal lifestyle change in the same way as are depression and addictions, all related to a loss of identity and cultural traditions (Napoli, 2002). For the

Haisla, the road to regaining their pride and their culture is a long one, but they have begun to walk it and they are committed to the full journey.

In addition to improved health for the Haisla, benefits of better diabetes management for the NHA and the Hospital would include fewer admissions and improved glycemic control. Hemoglobin A_{1c} (A_{1c}) is the indicator that corresponds with the past 3 months' blood sugar levels. According to Wagner (as cited in Clement, 2001), lower A_{1c} directly correlates with cost savings within 1 to 2 years of lowered blood glucose readings. Normal blood sugars would reflect improved lifestyle habits that reduce complications due to high blood sugars, such as kidney and cardiovascular disease, blindness, and amputations.

Possible Causes of the Problem

The Haisla are influenced by many factors that influence us all with regard to diabetes prevention. Easy access to market foods has increased the consumption of refined foods, which are low in dietary fibre and high in saturated fats and sugar. Lower energy expenditure due to reduced physical activity has tipped the scale, so to speak, in favour of weight gain and obesity.

Since the 1960s, numerous Aboriginal populations throughout the world support unusually high rates of Type 2 diabetes, with the highest incidence in the Arizona Pima Indians (O'Dea, 1994). However, while an Aboriginal genetic predisposition may exist, O'Dea cited other examples of Type 2 diabetes among the multi-ethnic groups in Mauritius, Nauruans, and other Pacific Islanders, and the emigrant Indian population. Consequently, in establishing the factors that contribute to diabetes, genetics plays only a part. To know the complete picture, the reasons for the transition away from the traditional lifestyle need to be examined.

One factor has been the tendency of Western medicine to focus on solely the body as the source of illness and the sign of health. In their survey of the incidence of diabetes in BC

First Nations health centres, Johnson, Martin, and Sarin (2002) concluded that general preventive initiatives must continue to include screening, nutrition and fitness education, and improved diabetic management directed at reducing complications. However, they failed to consider First Nations health beliefs and the impact of emotional, mental, and spiritual health. Alternately, the Aboriginal Diabetes Wellness Program coordinated by the Aboriginal Wellness Centre in Edmonton, closely links diabetes with stress and emphasizes the importance of mental, emotional, and spiritual healing (Gobert, 2000).

Many health care providers are uninformed about the stresses on First Nations cultures. One such stress is the residential school syndrome that weighs heavily in the community, according to the Diabetes Coordinator (personal communication, February 21, 2003), with far-reaching effects that only some are willing to face. Many previously known Aboriginal life skills were wiped out and, according to Miller (1996), the use of their own language was largely prohibited. The education provided was often substandard to that given to non-Aboriginals, often being directed at home economics skills for girls and horticulture and some trades, if they were lucky, for boys. Solomon Johnston (as cited in Miller, 1996) spoke of his residential school experience:

> The teachers only taught us enough so that we could just begin to read. The older girls taught us in the evening but during the day we cut wood, picked stones -- all the worst jobs. We didn't learn anything. We didn't know anything. I read only a little now. The only thing I know is how to survive and my dad taught me that, my dad and the old people. (p. 182)

Despite the inferior quality of education in many schools, this quote points out the vital influence of the elders, which the Haisla are seeking to re-establish. However, according to health centre staff, some elders are reluctant to open the door on the past for fear of reopening old wounds.

Other stressors resulting in compromised health, specific to Kitamaat Village, are addressed in the *Haisla Community Health Plan* (Willie & Knighton, 1998):

1. Reduction of stress and related occurrence of suicide, substance abuse, vandalism, family violence and Elder abuse.
2. Reduction of stress and related occurrences of sex abuse, teenage pregnancy and child neglect.
3. Development of community awareness and collective responsibility around sex abuse, FAS/FAE [Fetal Alcohol Spectrum Disorder], child neglect and lack of well-being of Elders.
4. Improvement of health-related behaviors and provision of an awareness of healthy alternative lifestyles.
5. Care and treatment of chronic illness.
6. Communicable disease control.
7. Elder support and prevention of Elder abuse.
8. Resolution of issues of past painful experiences that have created mental stress resulting in low self-esteem and self-worth, such as Residential school syndrome.
9. Addressing and improvement of all aspects of parenting. (pp. 9-10)

All of these issues create the environment that affects the prevalence of diabetes. These conditions result not only from Aboriginal historical influences, but also from present-day cultural beliefs, political structures, and health care systems.

Diabetes is a societal disease whose risk factors are well entrenched in the social fabric of our communities. In spite of many efforts toward preventing diabetes, risk factors and the number of Canadians with diabetes continue to increase. Although the National Diabetes Strategy Coordinating Committee (2003) stated that services for managing diabetes are making a difference, more people are being diagnosed and those with the condition live longer and develop complications from the disease. As a result, existing resources are being pushed to the limit (p. 2).

Potential Solutions

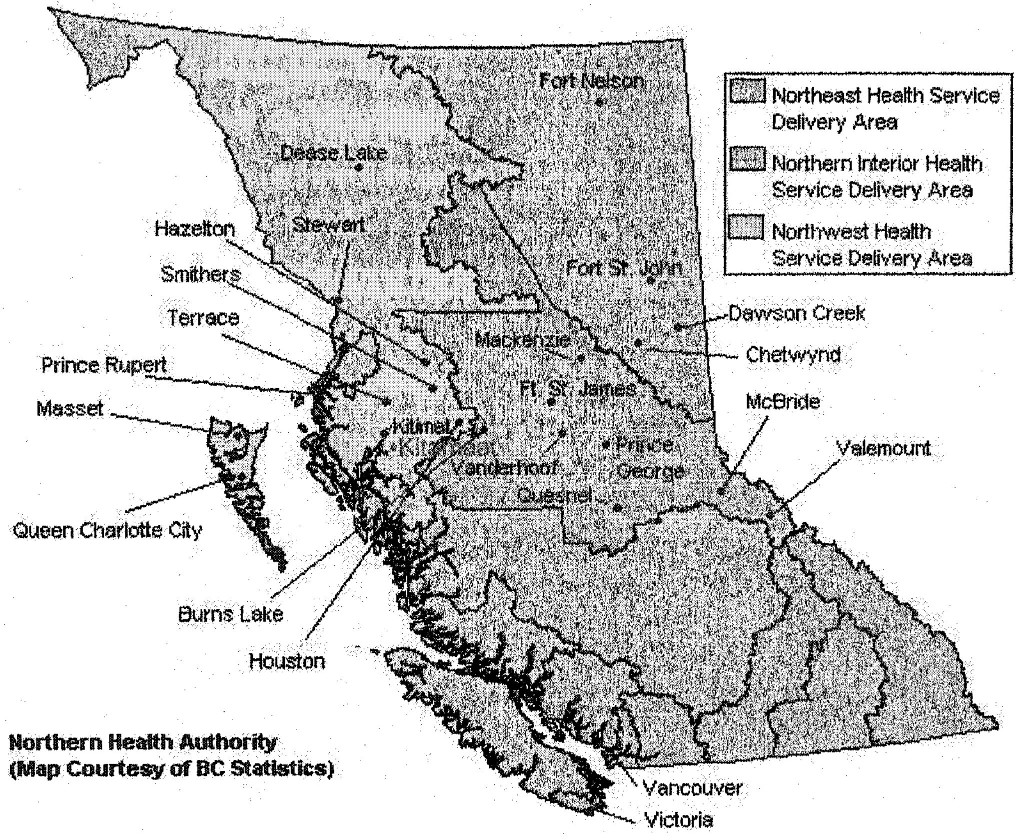
Haisla living in Kitimat have different privileges from those living in the village. Federal policies and band council direction dictate how health services are administered at the Haisla health centre, whereas the municipal hospital is regionally and provincially directed. This misalignment creates gaps in health care that can be resolved by interdisciplinary and intergovernmental communication, and coordinated programs. If restructuring does not occur, the price we will all pay is inestimable.

The Organization

The Northern Health Authority was formed in the provincial restructuring of December 2001, encompassing 16 previous regions and an area comprising 60% of the province. In 2000, there were approximately 320,000 people living within the NHA. Thirteen percent of the population is Aboriginal, the highest proportion in the province (Northern Health Authority, 2003a, para 3). A little over 6,000 people work for the NHA in over two dozen acute care facilities and 14 long-term care facilities, as well as public health units and offices providing specialized services (para 5,6).

The NHA is divided into three health service delivery areas, the Northwest, Northern Interior and Northeast. Each health service delivery area is divided into clusters. Kitimat is in the central cluster, with the Health Services Administrator, in charge of Kitimat, Terrace, Stewart and Dease Lake facilities, reporting to the Chief Operating Officer, Northwest Health Service Delivery Area in Prince Rupert. Neither Kitamaat Village nor any First Nations communities are shown on the following map; I superimposed Kitamaat to show its location (Figure 2). I wonder if we would work more closely with our Aboriginal neighbours if their communities were included on our maps.

Figure 2. Kitimat/Kitamaat Village as Part of the Northern Health Authority, Northwest Health Service Delivery Area (NHA, 2003c)



Northern Health Authority (Map Courtesy of BC Statistics)

Communication between these three health service delivery areas is achieved through regional directors at the area management level and chief operating officers at the executive level. Greater detail is provided in the organization chart (see appendix A), which shows how the NHA is comprised of interlinking of regions and clusters.

As described in the *Health Service Redesign and Budget Management Plan* (NHA, 2003b), the "Aboriginal Health Services Plan" was initiated in May 2003,

> To improve access to primary and secondary prevention programs, build capacity in front line and management [workers], and enhance working relationships between the NHA, First Nations and Inuit Health Branch, and other government departments.

> Community specific action plans will be developed in areas of common interest and opportunity to improve health or health services. (p. 3, last para.)

This project explores how to begin a working relationship between an NHA facility, Kitimat General Hospital and Health Centre, and a neighbouring First Nations health centre, Haisla Health Centre, to better meet the community's needs and interests. In the second chapter, I will review relevant organizational documents from both facilities, followed by a review of the literature that addresses the complexities of First Nations health improvement.

CHAPTER TWO – INFORMATION REVIEW

In this chapter, two types of literature will be reviewed, as background to the study outlined in chapter 1: organizational documents pertaining to the Northern Health Authority (NHA) and the Haisla Health Centre (Kitamaat Village); and supporting literature on First Nations history, generally and locally, the impact of political structures, and the effects on health and culture.

Review of Organizational Documents

There are primarily two organizations whose documents impact this project, the Haisla Health Centre – to be referred to as the health centre - and the NHA, specifically, the Kitimat General Hospital and Health Centre, to be referred to as the hospital. Information from the Health Centre was the most difficult to retrieve, which in itself is significant. The inaccessibility of documents made me wonder whether organizing information is not a priority, there was insufficient time to develop a storage system, or the organization preferred to protect the documents from scrutiny. I believed that once I explained their relevance to this project, I would be provided with the necessary documents.

Kitamaat Village

The most essential document required was a band council resolution that formally gave the approval of the chief and the council for the implementation of this project. It would indicate that they fully understood my intent and the mutual benefits this incentive could bring. I checked to see if there was a code of ethics specific to Kitamaat Village that I needed to follow; however, there was none. As pointed out by Hudson and Taylor-Henley (2001), I was responsible for ensuring that this research was done "*with* the community and not *on* the community" (p. 100). So, as they knew my intent, I had to trust that they would provide me with the most relevant documentation.

In 1998, a community health plan identified health needs of both the community and the participants. It initiated the hiring of an outside consultant to set up a health transfer plan, in 1999, from federally funded programs to run health care. The consultant, Lorna Morrison (2001), completed *the Kitamaat Village Home and Community Care Service Delivery Plan*, initiating the Home and Community Care Program that involves a Home Care Nurse/Program Coordinator and a Licensed Practical Nurse/ Diabetes Coordinator. In addition, there is provision for two part-time home support workers. The diabetes component is funded by a temporary government grant requiring yearly renewal under the federally funded Aboriginal Diabetes Initiative.

The following information sources would have helped me to better understand the Haisla culture and health situation, but I was unable to access them during the past year:

- The Na 'na 'kila Society is a Haisla initiative to explore and conserve their culture through documentation. Apparently, an anthropologist was working in Kitamaat Village, but we did not meet. In addition, Nancy Turner (personal communication, June 12, 2003), ethnobotanist at the University of Victoria, informed me of a study commissioned by the society that documented many traditional foods. I obtained only her books, not the study itself.
- The 1996 Kitamaat Village Dietary Survey described the results of a food frequency survey and two 24-hour food recall questionnaires conducted by a federal registered dietitian. The health centre administrator did not have a copy, and when I contacted the dietitian to see if she could provide me with one, I received no reply.

Until I was granted a band council resolution, I felt uncomfortable requesting documents from the health centre staff, as I was concerned about placing them in an awkward situation.

Northern Health Authority

With regard to NHA documents, according to the Chief Operating Officer (COO), Northwest Region, there was no NHA code of ethics to adhere to, provided I followed Royal Roads University's ethical guidelines and met the criteria of the university's Ethics Committee. The COO did advise me to keep the NHA' s vision, mission, and values statement in mind (Suzanne Johnston, personal communication, September 18, 2003):

VISION, MISSION, AND VALUES

The vision of Northern Health is to be a model of excellence in rural health care.

The mission of Northern Health is as follows:

1. Northern Health will build and strengthen the health of communities, relationships, and people in Northern BC;
2. We do this through community partnerships, health promotion, health services, learning, and research;
3. We will monitor progress by continually measuring service quality, access to service, our work life quality, and costs.

The key value of Northern Health is to live by our mission.

(Mark Karjaluoto, Director of Communications, NHA, personal communication, most recent revision, March 10, 2004)

The vision, mission, and values statement was a culmination of input from both senior management and all employees who wished to add their comments. The statement seems somewhat ambiguous, possibly reflecting the enormous number of changes that were occurring within the NHA at the time, one year after its formation.

Ethical Guidelines

In addition to adhering to the values statement, I was particularly sensitive to the need to comply with the following guidelines:

- Interagency Advisory Panel on Research Ethics (2003): "Section 6 – Research Involving Aboriginal Peoples"
- National Aboriginal Health Organization, First Nations Centre (2003): *Ethics Tool Kit: Ethics in Health Research.*

These documents incorporate standards from academia such as the Association of Canadian Universities for Northern Studies and the Tri-Council Policy Statement. In addition, they encompass ethical and research guidelines from the Royal Commission on Aboriginal Peoples and valuable lessons learned by First Nations in projects such as the Kahnawake Schools Diabetes Prevention Program (2004a).

In applying these guiding principles, I ensured respect for Indigenous cultural and intellectual property by

- Involving the village residents in all processes and decision making, including research methodology and presentation of data. Their perspective was retained in the reporting of all findings.
- Applying the findings only to the specific community (the Haisla), reflecting the importance of context.

- Ensuring that quotes that could only come from one person were used only with that person's consent.
- Assisting health centre staff to seek the knowledge they desired and fostering research capacity in the community.
- Honouring oral traditions and nurturing the retention of the Haisla language.
- Retaining original data and transcripts for 2 years, in compliance with RRU guidelines; if requested by the health centre administrator, the raw data would be transferred to a Kitamaat Village repository.
- Agreeing to "right to dissent" in the final reporting of results whereby, in cases where there is disagreement over the interpretation of the results, the researcher can go ahead and publish, but the community has the right to include a description of why they disagree and how *they* interpret the findings (National Aboriginal Health Organization [NAHO], First Nations Centre, 2003, p.10). In this way, the public can read both the study and the interpretation, allowing them to make an informed decision of their own.

By following these practices, I hope to have initiated "important outcomes of ethically sound participatory research: …ongoing capacity building of collaborators – for example, training, and better infrastructure, data collection, and storage – stronger receptivity to collaboration by researchers, stronger community voice in policy, and greater mutual trust" (Macauley et al., 1999, p. 774). Above all, the quality of the research shall be determined, according to Schnarch (as cited in NAHO, First Nations Centre, 2003), "by how good the methodology is [and] how useful the results are at the community level" (p. 8). The participants must feel that their time and effort is validated and productive. The *Ethics Tool Kit* also declared, "Right now, none of the non-First Nations codes say much about a community's right to control how the research is carried out, or how the research results are used" (p. 8). I fostered open dialogue to clarify these points and our participant/researcher roles throughout the research. Finally, on completion of the project, I disclosed, to the best of my ability, any limitations that might have impacted the research, such as time constraints or poorly understood directions.

Review of Supporting Literature

In assessing the current health situation faced by any First Nations community, whether from a political, medical, cultural, ecological, or philosophical viewpoint, a researcher needs to remember that the present is a reflection of how the community's members are coping with the injustices of the past while striving to be progressive. In this review of the supporting literature, I start by giving a sense of the impact of colonization as gleaned from the literature on First Nations peoples. This history contributes to who they are today. The legacy of European oppression resulted in dramatic changes in their family and community structure, their language, education, and communication links, their spiritual beliefs, and ultimately their health and their ability to be whole. This review helped me to walk softly, listen carefully, and know which questions needed asking, both of the people who generously gave me their time, and of myself.

The Impact of Colonialism

History of the Haisla.

The manner in which the First Nations were treated by the Europeans centuries ago has not been forgotten. The appropriation of land, disease that killed whole tribes, and cultural genocide has left deep scars in the approximately 1 million Aboriginals who remain in Canada today. The Haisla share this history of colonization.

The beginning of the 19th century marked the end of the reciprocal relationship the First Nations had developed with the new inhabitants. War between Great Britain and the United States had ceased; hence, Miller (1991) summarized, the Indians' military significance was now diminished in the eyes of the British planners (p. 83). The beaver had been overhunted and the fur trade was no longer as viable for the Europeans. Agricultural development could more than compensate except for the roadblock presented by Indians who wished to remain on their land. Cartier (as cited in Miller, 1991) concluded, "From the point of view of the European, the Indian had become irrelevant" (p. 84). This disregard for the lifeways of these First Nations was demonstrated in other areas too.

Education.

North American governments attempted to assimilate the First Nations, annihilate their language and culture, and decimate their way of life and sense of pride. Assimilation through evangelization, education, and agriculture became the policy. In addition, more coercive methods were inimical, expensive, and politically dangerous (Miller, 1996). The new settlers called this process "education."

Initially, some First Nations felt that becoming more educated in white man's ways would empower them. Chief Paulus Claus of the Bay of Quinte Mohawk (as cited in Miller, 1996) observed, "We are now driven far from our former homes, into the woods...unless we exert ourselves to conform to the ways of the white man...we shall be continually driven from the fertile lands" (pp. 81-82). Bands believed that concentrated settlements, each with its own manual labour school, would be economically advantageous. The government and the willing religious groups, specifically Roman Catholic, Anglican, and Methodist, jointly developed the system of industrial schools; however, they did not always share similar objectives regarding education versus religious conversion.

Some First Nations felt that becoming baptized would enable them to share the privileges enjoyed by the Europeans. Others, such as Chief Shawahnahness (as cited in Miller, 1996), agreed to have their children instructed, but he and his followers "had never engaged and had no wish to become Christians" (p. 80). Aboriginal parents had no idea of the reality that lay ahead for their children and how differently the white settlers viewed child rearing.

Seventeenth-century Indians regarded French mothers as "porcupines" (Miller, 1996) because of their stern attitudes toward their young. In contrast, Aboriginal parenting consisted of setting a positive example in the home, using subtle guidance by incorporating games into lessons, and relying on stories to create images of the desired actions. Discipline was never corporal but administered as ridicule in the form of public embarrassment or stories that warned of tragic consequences following a misdeed.

Residential schools, on the other hand, frequently used physical punishment. Because funding was limited and funds were often misused, the schools did not necessarily attract the cream of the crop of teachers or administrators. Miller (1996) mentioned a Whitehorse doctor describing the 1962 school staff at Carcross, Yukon, as being "a collection of ill equipped misfits and neurotics" (p. 320). Alcohol abuse was not uncommon among the priests; many of these so-called teachers were seen as no longer fit to serve in parishes. At the request of the bishop, an Oblate priest was removed from his post in Prince George because of excessive alcohol consumption; however, a well-intentioned school principal accepted him in Kamloops (Miller, 1996). Abuse was common, and Miller described this abuse as ranging from a slap on the side of the head for the non-use of English, to food deprivation and forced feeding of tainted food.

Traditional Practices Versus Christianity.

In addition to being restricted from speaking their native languages in the schools, First Nations were prohibited from following many of their traditions. These included an Aboriginal medicine practice called "Tamanawas," a type of dance involving "ritual cannibalism (involving dogs, corpses, and living individuals), including ritual biting" (Waldram, Herring, & Young, 1995, p. 118). Olson (1936) described various Haisla dances including the Nutlam dance, where a dog is killed and eaten, and the Tanish dance, where the prestigious dancer (the Sanaxet) consumed the flesh of dried corpses and imparted severe bites to honoured onlookers. A story was told to Olson about a Tsimshian chief in the 1860s who bestowed two child slaves upon the Sanaxet, who then proceeded to bite them until they were both dead (p. 177). It is little wonder that Christianity looked like an inviting alternative for remaining spiritually aligned.

In the years 1880 to 1950, Christianity drastically curtailed the traditional healing practices, due to church pressure on the government to ban such "unchristian acts." In reality, the measures were taken to assimilate the First Nations, rather than uphold Aboriginal spiritual and cultural practices. Christianity began locally, according to Robinson (1956), with Charles Amos, a Haisla who, in 1876, went by canoe on a trading trip to Victoria, where he learned about Christianity and was baptized. His new beliefs as the first missionary in Kitamaat were not welcomed when he returned. In fact, the shamans and secret society members, "nobility" according to Olson (1936), persecuted him because they believed that his new way of life threatened the social order they enjoyed. Eventually, however, most of the villagers were converted.

Additional support came from a white missionary, George Anderson, who arrived in the 1890s to teach at the Kitamaat Mission. Varley (1981) described how Anderson eventually married the daughter of the Haisla chief, the same "Charlie" Amos, to demonstrate to "the Indian people that we made no distinction…and considered them worthy of everything we had to give" (p. 24). These well-meaning sentiments were not shared by all, native or non-native. And when Anderson's bride died 10 months after the wedding, giving birth to a stillborn, the tragedy brought mixed opinions. The memory may linger to this day.

In 1884, the Northwest Coast feasting ceremonial system known as the "potlatch" was banned, largely at the insistence of the missionaries (Waldram et al., 1995, p. 16). This banning destroyed a key social structure. In addition to the redistribution of wealth, according to McMillan (as cited in Waldram et al., 1995), the potlatch "enabled individuals and families to recount their histories and reaffirm their hereditary right; hence, the potlatch served as an important institution reaffirming the oral tradition and history of the people" (p. 117). The idea behind a potlatch was to not only repay those who had previously bestowed favours or material goods, "but completely outdo them in the business of giving away wealth so that one's social position might be maintained or improved" (Robinson, 1956, p. 39). The most desired material was eulachon grease, because it could be traded or bartered to other First Nations. Eulachon, small herring-like fish, are still prized today.

In 1886, the potlatch ban was formalized in a new section of the Statutes of Canada (Waldram et al., 1995), making it "an indictable offence to participate in or encourage any Indian festival, dance or other celebration of which the giving away or paying or giving back of money, goods or articles of any sort forms a part or is a feature" (p. 118). This section continued, banning "any celebration or dance of which the wounding or mutilation of the dead or living body of any human being or animal forms a part or is a feature". The law remained unchanged until the 1951 revision of the Indian Act that removed most prohibitions, although "Canada's control over Indian lands and property, money, local government and Indian status remained" (Patterson, 2003, p. 9).

Spirituality.

The ultimate effect of such laws was to drive these and other religious and related healing practices underground. The Aboriginal view of "medicine" incorporates the belief that not only the physical body requires healing. Waldram et al. (1995) noted that one must include a kind of "power" in a spiritual sense, something influential on the lives of people, "which was difficult to know fully or understand, and which therefore required certain preventive, propitiating, and/or prophylactic activities to occur" (p. 100). Medicine, spirituality, and religion are one belief system, impossible for non-Aboriginal practitioners to disconnect.

Among Northwest Coast Aboriginal people, Trimble (as cited in Waldram et al., 1995) noted that soul loss was a common affliction evidenced by "lethargy, anorexia, changes in emotional status or behaviors, and overt physical conditions such as tremors or palsy-like symptoms…non-physical complaints might include the inability to attract a lover, or poor luck in hunting" (p. 102). Hallowell (as cited in Waldram et al., 1995) described how one's child could also be the bearer of the consequences of adult immorality and be struck with serous illnesses (p. 102). This sense of being punished for misdeeds through physical afflictions impacts how diabetes may be perceived in the Aboriginal community.

Ecological ties.

Also included in the spiritual realm are seasonal influences. The Haisla year was governed by seasonal activities, an influence that remains to this day. A highlight of the year was the September trip to Giltoyees Inlet or Foch Lagoon for picking salmonberries and huckleberries. This trip coincided with the mountain goat hunting season when families would camp together, women picking berries and men moving up onto the mountains to hunt goat. Robinson (1956) described how "berries were either dried or made into thick preserves; goat meat was barbecued then smoked and packed into airtight containers. In the evenings, feasting, singing and dancing around a large central fire celebrated the harvest" (p. 4). Feasts continue to play an important role in Haisla culture.

Importance of Family.

This sense of community remains, as demonstrated during the eulachon run in which many residents, young and old, move down the Douglas Channel to a fishing camp where they either dry the fish or boil them to extract the oil (Diabetes Coordinator, personal communication, March 18, 2003). These skills have been successfully integrated into their modern society. Other areas, such as childcare, have presented greater challenges.

Child abuse was not restricted to those who attended residential schools. By the early 1960s, both the American and Canadian governments recognized the deficiencies of residential schools and withdrew their support, thus allowing more Native children to live with their families. The first problem was that these families did not always look the way social workers believed a family should look. For example, single mothers living with grandparents raising the babies did not look like responsible parenthood to Christian white people. In the "Sixties Scoop" described in Benson (2001), children were literally abducted off reserves by social workers, prohibiting them from a life on-reserve and adopting them out to generally white families.

In 1984, Bradford Morse (as cited in Benson, 2001) listed five consequences of colonialism as probable causes of the Sixties Scoop:

- The destruction of traditional economies
- The disregard of traditional values by the social service system
- The resulting surrender of their values by Indian people
- The conflict between federal and provincial jurisdictions
- The continuing manifestations of colonialism in the apparent connection between the decline of residential schools and the rise of Indian child apprehensions. (p. 14)

Morse (as cited in Benson, 2001) summarized the results: parents despair and give up, and their children, "lost between two cultures…endure foster and group homes until they end up in jail or as victims of suicide" (p. 14). The children faced a range of consequences. Loneliness and identity confusion resulted in many suicide attempts; however, for some children, there was also gratitude for being raised in a loving, affluent home. What remained constant, nonetheless, was their deep sense of wanting to connect with Aboriginal culture and to know their roots.

The generational fallout of residential schools is reinforced by the difficulty First Nations people experienced in adjusting to life after attending a residential school and trying to earn a living:

> When an Indian comes out of these places it is like being put between two walls in a room and left hanging in the middle. On the one side are all the things he learned from his people and their way of life that was being wiped out, and on the other side are the

> white man's ways, which he could never fully understand since he never had the right amount of education and could not be part of it. There he is, hanging, in the middle of two cultures and he is not a white man and he is not an Indian (John Tootoosis, as cited in Miller, 1996, p. 386).

The loss of identity and self-confidence passes onto the children. Numerous Aboriginal women I spoke with expressed a similar experience of separation. Whether they grew up off the reserve and returned to the reserve through marriage or they left the reserve to seek further education, on their return they felt alienated, like outsiders.

These interwoven factors have served to unravel the fabric of many Aboriginal families. Despite deep love for their children, some Haisla parents have problematic parenting skills. Among the many contributing factors are ambiguous role models. The confusion over identity, shame, and a sense of hopelessness bode poorly for caring about one's health. The prevalence of abused mothers and children, and other abuses that constrains the family, further contribute to poor health practices.

The real problem is not just an Aboriginal issue, but is one that weakens the entire fabric of our North American society. Healing has begun, however, progressing faster and stronger in Aboriginal women than in the men (Robelin & Spears, 2003).

Non-Aboriginals have only begun to recognize the impact of their actions or lack of action. As the dominating people, according to Hingley (2000), Euro-Canadians not only have set the rules in their favour (you will come to us regularly, we will go to you occasionally), but also have created the labels to maintain oppression – for example, the use of terms such as "welfare cases" and "drunken Indians." "Post-colonialism" however, indicates that many of us wish to relegate colonialism to the history books and foster open, equal relationships with all people. In order to do so, Hingley summarized, "I must seek further knowledge and have those who have been oppressed inform me how these issues are to be defined and what needs to be done to create solutions" (p. 108). We must learn the colours and textures of each other's fabric of knowing.

The next section looks at how political directives attempt to strengthen the threads.

Political Influences: Governance and Health Care

Unlike health care in our hospitals and health units, which is directed by provincial health authorities, health care in First Nations communities was a federal responsibility until, for Kitamaat Village, the 1998 health transfer process began (M. Nyce, personal communication, January 26, 2004). This process entailed the band formulating a plan whereby appropriately skilled health professionals, hired by the band, assumed the services previously performed by First Nations and Inuit Health Branch (FNIHB - formerly Medical Services Branch) personnel.

The band's funding allowance is based on the number of First Nations people living on the reserve. Non-transferable resources that continue to be funded by FNIHB include upgrading of clinical nursing skills, centralized training, Indian and Inuit health careers, research, non-insured health benefits, and capital grants for facilities (Patterson, 2003). The federal programs available to First Nations living on reserve fall into two main groups. First are the community health services: public health nursing, Community Health Representatives, National Native Alcohol and Drug Abuse Program, Home and Community Care, and the Aboriginal Diabetes Initiative. Second are the wellness programs: Canadian Prenatal Nutrition Program, Brighter Futures/Building Healthy Communities, Aboriginal Headstart, plus those pertaining to HIV/AIDS, Fetal Alcohol Spectrum Disorder, tuberculosis, and dental health promotion (Lemchuk-Favel & Jock, 2004). In addition, the Non Insured Health Benefits program complement[s] provincial/territorial insured health care programs and include[s] drugs, medical transportation, dental care, vision care, medical supplies and equipment, [and] crisis intervention mental health counselling (First Nations and Inuit Health Branch, 2002, 1st para). The word "complements" does not mean extensively provides health care.

The process of health services transfer is determined by the autonomy of the band, their stage in the treaty negotiation process and, perhaps most importantly, the priorities established by the elected chief and council. A valid concern expressed by Indigenous people in Canada, Australia, and New Zealand is "that all three governments may be capitalizing on the discourse of self-determination to off-load services onto the shoulders of poorly-resourced Indigenous health services" (Lavoie, 2004, p. 19). They are gaining independence at the cost of their health.

Furthermore, federal monies, such as those for the Aboriginal Headstart program, are offered to those programs that submit the best proposals, thereby "disadvantaging small First Nations with limited access to technical expertise in grant application" (Lavoie, 2004, p. 13). The health services staff that could be delivering health services, must sacrifice time to fill out forms and attend meetings to learn how to fill out the forms. In addition, funding-agencies' working definition of culturally appropriate services often does not match First Nations' vision for the delivery of health care in their communities (Maar, 2004, p. 58). Contending with cultural and political pulls, Aboriginal health services workers face high turnover rates that also contribute to programs losing momentum. Improving local support from provincially funded staff is indicated.

Provincial health services operate independently from those on reserves, however, in order to obtain federal transfer payments, the provinces must provide hospital and physician coverage. Who is responsible for, and how to provide complete service is unclear to many providers. "The grey area between provincial jurisdiction and federal policy can be enormous for First Nations, affecting a wide range of services from mental health programming and home-based palliative care to community long-term care institutions" (Lemchuk-Favel & Jock, 2004, p. 39). This discrepancy has been seen in the Kitimat-Kitamaat region, with insufficient services in all of these areas.

Another source of restitution by the federal government is the Aboriginal Healing Foundation, in place until 2009, for the victims of residential school abuse. It is limited to addressing personal problems such as alcoholism, incest, suicide, and other physical abuse. Critics include Phil Lane, Jr. (as cited in Myers, 2003), hereditary chief of the Yankton Dakota and Chicksaw tribes in Alberta, who has stated, "The damage to identity, which is connected to language, kinship relations, spiritual and cultural relationships, is every bit as important as the physical and sexual abuse" (p. 38). As in many government systems, a silo mentality has ignored important relationships and has focused only on the obvious.

Duplication of services exists in some areas, and yet broad gaps remain in others. Federal, provincial, and territorial governments have begun to recognize the gaps and overlaps with the formation of the Pan-Canadian Healthy Living Strategy (Health Canada, 2003b). The June 2003 Healthy Living Symposium held in Toronto concluded that Aboriginal peoples require a distinct action plan that is culturally relevant and wholistic in its approach (para. 9). After participants discussed all of the personal and systemic barriers to improving health status, key areas for leaders to address emerged. Of note was input from Aboriginal participants, who emphasized that

> Healthy eating and physical activity must not be addressed in isolation from the other challenges currently facing many Aboriginal communities… rapidly changing lifestyles and increases in sedentary leisure especially for youth, poor access to health care facilities and professionals, lack of social opportunities, low self-esteem. (Health Canada, 2003b, Moving Ahead, Challenges to Action, final para.)

The reality appears to be that what we, as health care providers, have identified as underlying factors that only influence outcomes, such as culture, poverty, and language, may in fact be at the foundation and may be the critical determinants of successful health interventions.

In The Picture of Health, the BC Ministry of Health Planning (2002) identified seven major Aboriginal health issues: infant health, tobacco use, alcohol and drugs, HIV/AIDS, diabetes, injuries, and primary health care (p. 56). All of these are influenced by poverty, hopelessness, and a loss of pride. Balancing support of these needs with the economic and self-governance needs of the Haisla First Nation falls onto the shoulders of the elected officials. Kitamaat Village has a newly elected band council and a re-elected chief, whose priorities we must understand to see how they impinge on diabetes and health care support.

Aboriginal Health Care in a Systems Context

A review of systems theory is relevant to my research focus, because nothing on this planet or in this universe is totally independent; everything exists in relationship to something else. Indigenous cultures around the world have felt and incorporated this connection in all parts of their lives for millennia.

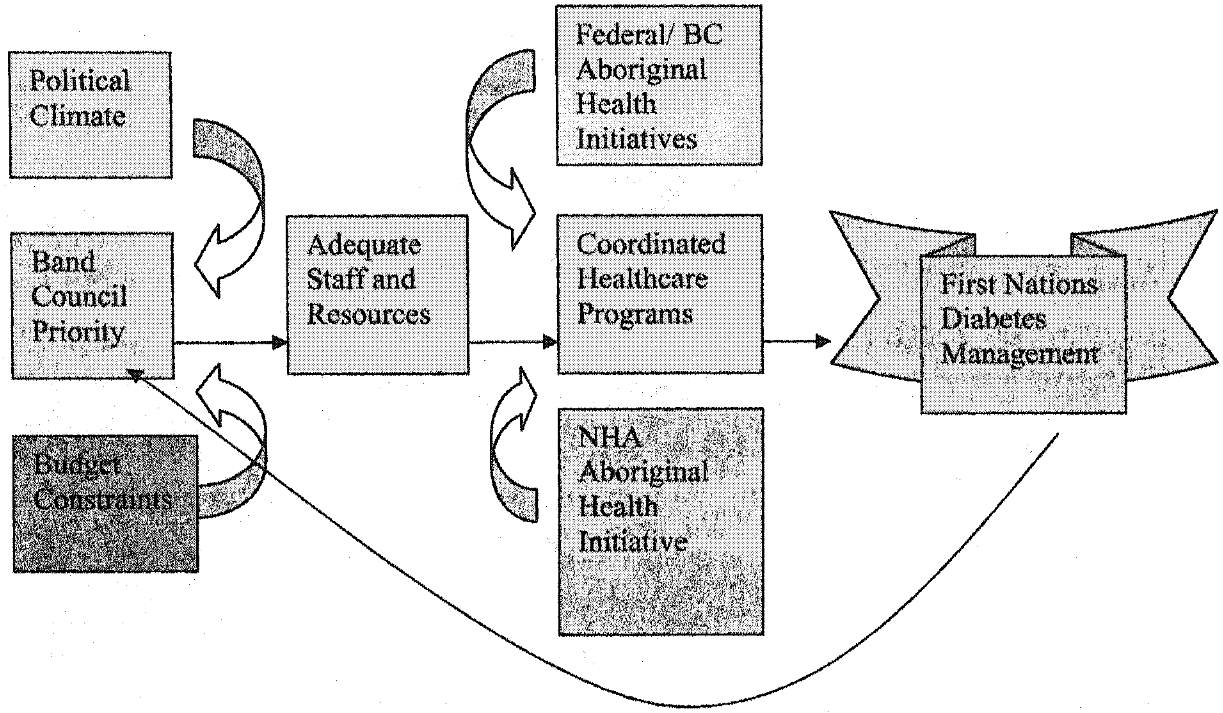
Just like living systems, organizations are complex adaptive systems. Constantly in existence is the need to change; change is about to occur or is occurring, or adaptation has taken place. This notion of life as a fluid, as a changing process, stated Wheatley (as cited by Flower, 1993), needs to become embedded in our organizational thinking (see Planning, para 2). This acceptance of change is dramatically enhanced when the contributions of the smallest components of the organism are honoured for the vital functions they perform.

Kitamaat Village as a System.

Viewing Kitamaat Village as a complex adaptive system leads to a heightened awareness of how critical the people making the changes are and how the changes impact them. In Figure 3, I propose a model for the current systems affecting the management of diabetes in Kitamaat Village.

When the health centre staff are given the authority and the funding for adequate personnel, program implementation and training, they are more capable of utilizing other funding (by having time to write proposals, as an example), identifying their true needs, and working with the NHA to improve diabetes management. The employees are able to withstand changes in the political climate because of having developed greater stability with local supports. Local support provides flexibility for contending with changes such as government policy. The system's strength is based on the people involved, not the bureaucratic structure.

Figure 3. Model of Systems Affecting Kitamaat Diabetes Management (adapted from Shibley, 2001a)



Shibley (2001a) emphasized that in a system, the quality of the relationships between elements is more important then the quality of the elements themselves. As professional helpers, we may be tempted to fix symptoms, rather than the root causes of a problem. Sometimes we mistake the external features of a situation – for example, a chronic disease such as diabetes or obesity – as the problem elements. The blatancy of external features are symptoms that often divert our attention away from examining the *influences* on the elements. Briefly defined, a systems approach looks at these influences and the way they connect the elements.

Elizabeth Fadell (as cited in Shibley, 2001b) challenged the term "systems thinking" when she said,

> I wish they had never called it systems thinking. It has always struck me as far more like a sensibility, or as sensing connections. Sensing these connections is more than [a]

> "head" thing, although I really don't believe there actually is such a thing as a perspective just "coming from someone's head", but that's another conversation. Head and heart and gut are connected; after all they are part of a system. (in A Systemic Sensibility, para 18).

Engaging all people involved in the system assembled for discussion may initially lead to chaos. However, chaos in a respectful, supportive environment leads to creativity and experimentation, the freedom to try new ideas. Wheatley (as cited in Flower, 1993) pointed out:

> People get scared and frustrated, and they want to problem-solve their way out of the chaos. But we don't let them. We keep them generating even more information. Finally they let go. Once they let go, they have the capacity to come up with bold solutions that integrate all of the information. At the other side of chaos you get a new kind of order, an order that is adaptive, that is transforming, that is all the things we want in an organization to be. (p. 6, first para).

This important intermediary step is critical for creating order and finding a solution that works for everyone. If we respect all viewpoints and allow open dialogue, a spirit of cooperation and collaboration will ensue and creativity will flourish. This openness is also necessary for honouring differing worldviews and ways of learning.

Learning.

Indigenous thought is more intuitive and ecologically anchored as a result of a close association with the earth and the surrounding universe including the spiritual world. Whereas Western scientists speculate on interactions within a local ecosystem developed from global studies, Indigenous people internalize much more information about a small geographic area derived from ecological knowledge and from generations having learned from one another. Battiste and Henderson (2000) described this knowledge as "operating instructions for the land, given to them from time to time by the Creator and the spirit world, not just through revelations or dreams but also through frequent contacts with the minds and spirits of animals and plants" (pp. 44-45). The succeeding generations do not blindly accept what their predecessors taught; rather, they recognize that for each individual in each new circumstance, other variables may need consideration, and thus each personal reality is respected. These differing ways of acquiring and defining knowledge result in diverse worldviews.

Eurocentric or Western philosophy tends to categorize sciences, humanities, and psychology and is "based on desires and assumptions, using reason to explain and structure the world …However, because of the endless diversity of these constructs, Eurocentric thinkers quarrel among themselves if they have to learn more than one version of an artificial reality" (Battiste & Henderson, 2000, pp. 28-29). This way of procuring knowledge leads to the dismissal of alternative philosophies and the subjugation of new bodies of thought.

Furthermore, Bohm (1980) demonstrated how this "fragmentary self-world view" is contrary to the wholeness and integrity that human beings seek, resulting in "a thoroughgoing confusion that tends to permeate every phase of life, and that ultimately makes impossible the solution of individual and social problems" (p. 27). This Eurocentric worldview, where "the people who have the power to decide what a thing will be called have the power to decide reality" (Battiste & Henderson, 2000, p. 74), directly opposes Indigenous thought and how the world is experienced. Our worldview determines all life expression, including modes of learning.

How Aboriginal learning occurs must be considered for First Nations people's effective self-determination, whether related to self-governance or self-monitored health habits. According to Kawagley (as cited in Battiste & Henderson, 2000), "[Indigenous] personal cognitive maps are created by humour, humility, tolerance, observation, experience, social interaction, and listening to the conversations and interrogations of the natural and spiritual worlds" (p. 36). Subtleties of thought are reflected in our language.

Language.

Language is essential for conveying the collective consciousness. Indigenous languages are verb-based, reflecting the inter-relational quality of all things and a respect for a personal worldview. The importance of silence is key, for silence allows for the manifesting of thoughts and feelings. The poetry of Aboriginal language brings with it a richness of meaning that noun-based English cannot fulfill. A rheomode is the term coined by Bohm (1980), a quantum physicist, to describe this language construct, where the verb is given the primary focus in recognition of the interplay and movement of all that exists. For example, Indigenous thought describes, "I saw the hummingbird" as "The hummingbird presented itself to me," placing greater emphasis on the verb associated with the non-human living being. Events happen from perspectives other than our own; we are a part of, not at the centre of, all things.

Noun-based, factual information sessions, frequently taught by health care professionals including the author, meet few of these cognitive needs. So I would postulate that when teaching an Aboriginal group, we let them define diabetes in their language (or terms), in a way that is meaningful for them, allowing them to verbalize how it is affecting their lives. By listening to them, we will understand what support they need.

For example, if the Haisla elders participate in translating their diabetes experiences into Haisla, it is possible that a new way of conceptualizing their disease will help them put it into context for younger generations. Expression in Haisla will help to validate their truths and their experiences around all aspects concerning diabetes that the health care field may gloss over. In addition, language translation (from English to Haisla) may identify feelings and fears that previously were kept hidden, either consciously or unconsciously. Finally, storytelling is a major form of communication of values, beliefs, and codes of behaviour. Battiste and Henderson (2000) clarified that "stories transmit validated experience; they also renew, awaken, and honor spiritual forces [therefore it is]...important to learn the existing oral legacy" (p. 77). Perhaps this project will add significance to the support of Haisla language training.

It is one thing to reach a person's creative right brain but quite another to reach their soul. Language can help to bridge that gap, being built upon the wisdom and spirituality of the ancestors. Due to the many forms of communication, Chamberlin (2000) cautioned against even the use of the words "oral" and "written," as the distinction between them is rather blurred. He illustrated his point:

> Every culture has eyes and ears, as it were, and the woven and beaded belts and blankets, the carved and painted trays, the poles, doors, veranda posts, canes and sticks, masks, hats, and chests that are variously part of many oral performances among Aboriginal peoples, especially those central to sacred or secular traditions...*these* forms of writing are often just as important as the stories and songs. (p. 138)

These forms are not simply beautiful objects, works of art, or part of a sacred ritual, but are sentinels of knowledge from the past. In his discussion of differing ways people can describe multicultural relations, Janzen (1997) explored the impact of language and literacy, race, religion, culture, and political tradition. He illustrated how it is impossible "to express certain beliefs and feelings outside the boundaries of specific psycho-cultural-linguistic traditions" (p. 66). We can only express what we know and how we know it from what we have been taught and what we have experienced.

In recognizing culturally specific language and communication styles, Tripp-Reimer, Choi, Kelley and Enslein (2001), suggested indirect communication rather than direct questioning or instruction be employed particularly with Native America and Hispanic peoples.

> Applied to teaching, the educator present[s] as a colleague rather than as an authority; not requiring direct or immediate responses from audience members; establishing ties through relatives, friends, or common locations; using indirect referencing (e.g., saying that "someone who has such a problem, might do the following" rather than using a directive approach); incorporating humor during serious discussion to provide balanced communication; and avoiding confrontation. (Delivery of culturally competent…intercultural communication, para 2)

Accepting another's way of expression as equal to our own, despite not fully understanding it, is an essential step in expanding our own knowledge and creating deeper, trusting relationships.

The Land.

In addition to language playing an important role in reflecting the systems that influence the Haisla, so does their interaction with the land. Natural resources are not just commodities used for creating employment and fuelling an affluent lifestyle. Indigenous people feel spiritually connected to all that the earth provides, whether it is rock, bear, or tree, this connection helping to shape their expressions and language.

In the early 1900s, foresters representing the government approached some Tsimshian wishing to claim some of their land. One Tsimshian responded, "If this is your land, where are your stories?" (Chamberlin, 2000, p.126). As described in the *Ethics Tool Kit* (NAHO, First Nations Centre, 2003), stories explain, teach, and entertain. They are the place where facts and feelings meet, and so they are central to civilization (p. 7).

We may fail to recognize how connected we are to the land of our ancestors, largely because for many of us, so much has changed and many of us have moved from our homeland. And yet mountains still call to us, as do lakes and oceans, all remaining constant but dynamic.

The environment affects thought and memory, because the actions of our predecessors influenced the land, which then shaped their thoughts, and the cycle continued. Current thought, stated Bohm (1980), comprises

> Only a view of knowledge as an integral part of the total flux of process may lead generally to a more harmonious and orderly approach to life as a whole rather than a static and fragmentary view, which does not treat knowledge as a process, and which splits knowledge off from the rest of reality. (p. 63)

The land is not simply geographic; it is the wellspring of intuition, generational grounding, and spiritual expression, and a source from which to simply be. Depletion of resources is a worldwide concern, particularly to Indigenous peoples whose heritage, customs, artistic expression, and sense of who they are depend on the bounty that surrounds them. When a source of life diminishes, so does their sense of security and renewal.

In the case of the Haisla, health centre staff expressed how the depletion of local salmon stocks has greater consequences than fewer salmon being consumed. The act of salmon fishing was a community event in which, when the boats returned bearing hundreds of salmon, many families and generations came together to preserve them. Sharing in the work was rewarded with sharing the spoils.

The salmon or eulachon harvest was a source of community pride. The trading of these abundant fish allowed for valued interaction with Interior Aboriginal groups, further fostering a sense of importance. As specified in Battiste and Henderson (2000), "Each clan or community has been associated, for centuries, with the subspecies (or 'runs') of salmon that return annually to its territory and that are viewed as its kinfolk. The dignity and honor of each community depends on the ability to hold feasts and share these fish with others" (p. 66). A health centre employee described how with the decreased salmon runs, sharing two or three salmon becomes difficult. Traditional food consumption then becomes a question of who can afford the right equipment to reach its source. The dwindling plant, game, and fish resources lead not only to an increased consumption of market foods, but also to a breakdown of the community inter-connectedness as their dependence on one another for survival decreases.

This sense of a crumbling lifestyle is also pervasive among the Haida on Haida Gwaii (Queen Charlotte Islands). In purchasing more store-bought foods and doing less activity to gather and hunt food, the participants in the *Haida Gwaii Diabetes Project* expressed feelings of uselessness and social isolation they had not previously experienced (Herbert et al., 1996). These feelings, in addition to the ones experienced about diabetes, contributed to a sense of fatalism in many. The findings of Hebert et al. support this loss:

> For some [Haida], naming diabetes as an illness and taking active steps to prevent it or delay its onset was seen as increasing the likelihood of developing diabetes. For others, developing diabetes reduces their interest and participation in traditional ways (p. 35).

I believe this sense of helplessness directly relates to the loss of traditions and spiritual security.

Creativity and spirituality are intertwined in Indigenous thought. Spiritual teachings are from elders and relatives in the form of lengthy stories, conversations, prayers, songs and rituals. Evidence of spirit is not only from within but all around, as described by Bohm (1980): "The proper order of operation of the mind requires an overall grasp of what is generally known, not only in formal, logical, mathematical terms, but also intuitively, in images, feelings, poetic usages of language" (p. xiv). The Indigenous relationship with the land correlates with spiritual sustenance. The protection of sacred sites and artifacts is essential for the spiritual health of Aboriginal communities and the integrity of the total system.

The next section explores a sampling of some collaborative Aboriginal diabetes programs in Canada that are effectively improving health through creativity and a whole health approach.

Successful Aboriginal Diabetes Treatment Programs

In the past, Aboriginal diabetes research has often neglected the worldview of the group being studied. In a study of the Health Belief Model as it related to Type 2 diabetes beliefs in a British Columbia Aboriginal population, Daniel and Messer (2002) found that when people more clearly perceived the severity of the disease, they were better able to control blood sugar levels. However, the authors admitted that the Health Belief Model Diabetes Scale may not have "captured salient beliefs held by the Aboriginal population surveyed" (p. 9). A survey may not accurately reflect the resultant fears, guilt, hopelessness, and sense of loss that diabetes can incur. The idea that family members come first and one's own needs come second, according to Pember (2002), is deeply embedded in native cultures (para 7). Lorelei

DeCora, an Indian Health Service nurse in the USA, reflected (as cited in Pember, 2002), "The answer lies in our traditions. The answer to everything we are facing lies within our traditions"(para 9). Working with the Aboriginal population to be surveyed, and not just subjecting them to research, allows the researcher access to their beliefs and traditions that must included in any intervention for lasting behavioural change to ensue.

Quesnel.

The Quesnel Tillicum Society Native Friendship Centre (n.d.) has developed an excellent Web site directed at both diabetes treatment and chronic disease management. It is geared for use with a school-aged audience or adults who would also be most likely to use the Internet.

The Web site uses appealing and simple language to address critical issues around diabetes including stress management and the importance of laughter. It also features many photos and other visual images. A two-page newsletter is available highlighting the next information session and serving as a useful educational handout (Quesnel Tillicum Society Native Friendship Centre, 2003).

The Quesnel approach is a definite role model to consider in establishing further diabetes programs in the Kitimat Valley area. The next example also incorporates a training program for diabetes outreach workers.

Dryden.

In Dryden, Ontario, a partnership was formed in 2000 between the Ontario Metis Aboriginal Association, the Dryden Native Friendship Centre, the Dryden Regional Health Centre, which is the hospital that serves the district, and the Dryden Diabetes Centre. They developed a series of workshops around the management and prevention of Type 2 diabetes.

The Urban Aboriginal Diabetes Community Workshop Program, in collaboration with Lifescan, who provided free glucometers and additional funding, resulted in an Aboriginal Diabetes Outreach Worker education program to improve support to those with diabetes in long-term care and in the community. This program has evolved into The Healing Trail (2001a) that incorporates the knowledge of Western medicine while enabling outreach workers to focus on traditional methods and approaches to develop wholistic prevention and awareness programs at a grassroots level (para 6). Elders are involved to impart their history, their stories, their frankness, and their wisdom.

Included in The Healing Trail (2001a) Web site, on the homepage, is a "Good $ense Food Box" brochure and application form. Volunteers from the Food Bank assemble boxes of top-quality fruits and vegetables supplied by local grocery stores and sell them for $20. Photos of activities and participants speak volumes about the community participation, sessions with outreach workers and those they will help. In addition, the Web site has photos from major events such as the January 2003 Northwest Region (of Ontario) Diabetes Conference and Health Fair that the local health centre organized, bringing in a variety of guest speakers including the Diabetes Advisor, Ministry of Health and Long Term Care, and representatives from the National Aboriginal Diabetes Association. Finally, a descriptive summary of the Medicine Wheel is presented, incorporating a clear graphic that outlines how to express emotions depicting the seven natural ways of healing (The Healing Trail, 2001b).

The Healing Trail Web site lacks the simple graphics of the Quesnel Native Friendship Centre site, but outlines symptoms, types of diabetes, prevention tips, recipes, and contact/workshop information. For example, a recipe of the month is presented, adding to the appeal of the Web site and, if improved on, could be a useful resource. The Blueberry Pancake recipe is analyzed into questionable diabetic choices and does not indicate the size of a serving.

The next example involves academic researchers collaborating with a large community and focusing on diabetes prevention in children more than in adults, plus providing academic training for health professionals.

Kahnawake.

The largest program, the Kahnawake Schools Diabetes Prevention Project (KSDPP), is at Kahnawake, a Mohawk community with a population of about 7,200, 15 km southwest of Montreal. Researchers from the University of McGill have received funding from the Canadian Institutes of Health Research for the period 2001-2006 to undertake the following:

a. Complete a 10 year evaluation of the Kahnawake Schools Diabetes Prevention Project in Kahnawake.
b. Evaluate how the KSDPP project is disseminated and adapted throughout a network of Aboriginal communities in Canada.
c. Offer academic training to Master's, PhD, and postdoctoral students interested in diabetes prevention.
d. Offer training to Aboriginal community researchers (Kahnawake Schools Diabetes Prevention Project, 2004a).

The Web site effectively summarizes the complications of diabetes and their impact, and the projects' goals and strategies. With the community, the KSDPP has developed a vision that encompasses daily activity, healthy eating, family gardens and traditional food gathering, and community responsibility to maintain health for "the future Seven Generations." The intervention program targets the schools and is centred on living in balance. As a participative action research project, it involves community members such as teachers, the youth centre, and sports groups in developing programs. Actual intervention starts simply: students walk 20 minutes around the school daily, no junk food is allowed into the school or sold at the school, a bicycle and walking path is being constructed, and healthy foods that honour tradition are served at community events. The successful Mohawk Miles Walking Club increased walking in the community fivefold. Family recreation plus gymnastics, line dancing, and volleyball are other activities offered.

An exciting aspect is a training program offered for others working in Aboriginal communities, which teaches program development and sustainability. At $1,000 for 4 days, it may be a cost that saves time and resources in the end. Participants develop actual programs to implement in their home communities (Kahnawake Schools Diabetes Prevention Project, 2004c).

Conclusion

As emphasized by Battiste and Henderson (2000), a key Indigenous belief is living in relationship to all that is. Understanding the concept of relationship between diabetes and future generations plus the interrelationships of the symptoms and etiology of diabetes may be critical for establishing prevention and treatment programs. On the other hand, working with people from other cultures may be less about learning about their particular customs and beliefs, and more about considering our own assumptions, awareness of privilege, and openness to an improved understanding of ourselves.

This chapter has reviewed key information that influences the manner in which any research on First Nations groups must proceed. The next chapter presents a description of the methodology that developed as a result of this background.

CHAPTER THREE – RESEARCH METHODOLOGY

This chapter identifies my reasons for choosing qualitative methods of study and the considerations involved in gathering the data. The detailed description of the conduct of the study that follows reflects the changeable nature of research plans, and the importance of the participants' input in the evolution of the research.

Research Methods

Choice of Methodology

According to the Haisla health centre staff, residents show considerable diversity in attitudes and beliefs even among similar age groups (Diabetes Coordinator, personal conversation, March 21, 2003). In ethnographic and participatory research, to best analyze this breadth of opinion, Olson (1999) suggested the incorporation of these themes: local/cultural conceptualizations of foods, health beliefs (including etiologies and metaphors of diabetes), and conceptions of the body and how it works (p. 190). The time frame for this project did not allow for extensive study in each of these areas; however, interviewing participants about their experience with diabetes would test if these themes evolved and reoccurred. Qualitative, participatory research would best reflect the needs of the Haisla.

Participatory action research (PAR) is "a means of putting research capabilities in the hands of the deprived and disenfranchised people so that they can transform their lives for themselves" (Park, as cited in Hagey, 1997, p. 1). PAR engages the researcher as a participant, inclusive of everyone involved in creating new knowledge and determining the questions that frame the methodology. Validating participants' experience first requires, according to Kirby and McKenna (1989), intersubjectivity: an authentic dialogue between all participants in the research process in which all are respected as equally knowing subjects (p. 129). This open parity results in relationship building and the development of trust. Second, all participants have a contextual quality; their environment, their past, and their beliefs must be carefully considered. Critical reflection expands on what are the influences that bear on the present-day person.

Intersubjectivity and critical reflection ensure that "we are able to hear and affirm the words and experiences of the research participants and at the same time be able to critically reflect on the structures that influence the actualities of their lives" (Kirby & McKenna, 1989, p. 130). The overarching goal of this project is to enable all parties involved to achieve a better understanding of past experiences, present circumstances, and future possibilities.

In considering my main research question, "In a First Nations community/health centre, what factors contribute to an effective diabetes program?" respecting the needs of the residents with diabetes was uppermost in my mind. Given the oral culture and history of First Nations peoples, individual interviews would allow participants to express themselves as freely as possible, with the option of sharing deeper concerns. As Palys (1997) stated, by interviewing people about their past, we "recover" parts of history that might otherwise have been lost (p. 160). By reconnecting with our history, we rediscover ourselves.

Researcher Self-Awareness

While seeking to understand the participants' beliefs, I needed an awareness of my assumptions and the impact of my presence in Kitamaat Village. I entered this project with an "interpretive framework," knowing the reality of the Haisla and their "lived experience" are different from mine and that I must ensure I account for my subjectivity (Fenwick & Parsons, 2003). My desired outcomes included "making explicit human values, relationships, meanings, beliefs…[and] understanding relationship between culture, language, and people's knowledge" (Fenwick & Parsons, 2003, p. 13). For example, the community health representative (CHR) clarified that there was no Haisla word for "diabetes" or "blood sugar." How did this language difference influence Haisla learning about these concepts?

I was aware of being perceived as an educated, possibly small, white woman. While unable to change their perceptions, I could acknowledge how their ways of knowing differed from my own, and also how their perceptions of me as a researcher might affect the research process. Thus I examined both the external events that contributed to my perception of another culture and the internal events that have affected how I perceive. I could then be fully present in the process of this project. I wanted to become a "connected knower" who begins "with an interest in the facts of other people's lives, but [then shifts] the focus to other people's ways of thinking" (Belenky, Clinchy, Goldberger, & Tarule, 1986, p. 115). I knew I would only catch glimpses of Haisla thinking in the short time frame of this project.

I listened to what was said and not said, while learning as much as I could about the participants in the limited time. I realized that I would be making observations *during* data collection; however, "[observation] is particularly important in the beginning stages because of its role in informing us about appropriate areas of investigation and in developing a sound researcher-other relationship" (Glesne & Peshkin, 1992, p. 40). I had to let go of feeling pressed for time, so I could immerse myself in the experience of others.

I wanted to allow time for silence and learn more about the Haisla peoples' subtle sense of humour. I considered that "participant observers are selectively present in that they hold back their words and watch carefully what they say when they do talk" (Glesne & Peshkin, 1992, p. 58). I wanted to ensure that any questions I asked were the right questions, "right" in the sense that they promoted the modelling of the project by the participants, rather than by the researcher. In addition, by sharing my biography at the beginning, as suggested by Palys (1997), the participants – my research colleagues – were more open to sharing theirs. My main role as facilitator and reflector was to help them to add form to how they already felt. My greatest fear was that they would not trust me; the greatest satisfaction I could derive would be their confidence.

Ethical issues in working with Aboriginal groups were always in the forefront of my mind, given their history of subjugation by non-Aboriginals. Demonstrating the transparency of my intent through seeking confirmation of my understanding and requesting continuous input from my Kitamaat colleagues helped me to form solid relationships. I frequently referred to the *Ethics Tool Kit* (National Aboriginal Health Organization, First Nations Centre, 2003) to ensure due respect for the participants.

Data-Gathering Tools

I was careful to regard data gathering as a process. First, I needed to get to know the participants, to appreciate what they might find most valuable for me to study, and to give them the opportunity to get to know me. Next, I needed to formalize my intent in writing and obtain written approval from the band council and Royal Roads University. Finally, I had to ensure that the participants supported the direction I took with this study.

Preliminaries

The health centre administrator told me that the Haisla had been "studied" before; sometimes they received the research results and sometimes not. Over the course of Spring 2003, I travelled to the village for preparatory meetings with the health centre staff, to determine how my research might contribute to their health-care needs. I also met with health services consultant, Lorna Morrison, who had prepared a village health needs assessment based on the residents' input.

By the end of May, I gave copies of my prospectus and a written confirmation of my intended methodology to health centre staff. I wanted to avert any misgivings they might have before the initiation of the data collection. On my return from the second Residence in the MALT program at the end of June, and prior to any further work on the reserve, I requested the formality of a band council resolution to ensure the chief and council's approval of my research project. Final approval was delayed owing to council and staff vacations and other unforeseen circumstances. Consequently, because of the commitment and enthusiasm of the staff, I initiated the groundwork of my data collection solely with the verbal approval of the health centre administrator and the encouragement of her staff. The band council finally gave its written approval at the end of September.

Participant Support

Initially, I thought that the CHR would choose the participants for the study, as she had lived in the village for most of her life, knew the culture and the people personally, and above all was well trusted. Further discussions with her made me realize that an introductory luncheon would provide a more appropriate introduction to the research. Potential participants would be given the opportunity to meet me, examine the questionnaire to be used in the interview, and ask questions, fostering their trust in me. The CHR reminded me again of the repeated studies and questionnaires that have involved the Haisla, and of their possible reluctance in contributing to yet another study.

In addition, the foods served at the luncheon would demonstrate how healthy eating could incorporate traditional foods. Whole grain, low fat bannock, for example, would reflect the findings of Gittelsohn et al. (1998) that a high consumption of foods high in fat and low in fibre substantially increased the risk of diabetes.

At the luncheon, I described how these interviews would help to determine their current needs as Haisla residents with diabetes. I also read out the following points, which were summarized on the consent form that was available for them to take home (see Appendix B, Consent Form).

- Interviews are voluntary and participants may opt out at any time.
- To ensure the most accurate data collection, interviews will be tape-recorded unless the person being interviewed objects. The data will be erased after transcription, unless a participant requests otherwise. If at any time someone decides to remove him- or herself from the process, the data will be erased immediately.

- Participant information will be kept confidential. Questionnaires will be numbered and kept secure in my office, with the interviewee names and codes kept in a separate location. Names will not be used other than to establish data reliability by the researcher. Pseudonyms or blanks will be used if others' names are mentioned.
- Participants may refuse to answer any question(s).
- The CHR will accompany the interviewer to the participants' homes, if that is the location agreed on, to provide an introduction and translation if necessary.
- The hour-long interview will occur at a pre-arranged time determined by the participant and the CHR; participants will be reminded of the importance of advance notification if they cannot keep the appointment.

The CHR was given copies of the consent form and the interview questionnaire, so she could give them to interested participants who were unable to attend the luncheon but wished to be interviewed, allowing them time to think about their answers in advance.

Before the questions were given to participants, I took care to have the CHR review them for appropriate wording and content. The questions were also assessed according to the Flesch-Kincaid formula for readability (Flesch-Kincaid Reading Measures, n.d.), as were subsequent written materials. I had intended for the CHR and I to select one resident for a pilot test as recommended by Hubbard and Power (1993), to determine if the questionnaire was adequately specific, if it contained too many questions, or if the right questions were being asked. Instead, I tested the questions initially with a first-year MALT learner who had Type 2 diabetes, and then obtained final endorsement from the CHR (see Appendix C – Questionnaire for Residents).

Data Analysis and Organization

After each interview that the CHR attended, I met with her for triangulation, to obtain her impression of the interaction, verbal and non-verbal, current and past. I then recorded my insights based on the following questions:

- What did I sense during the interview? Did this change over the course of the hour?
- How did the person's words correlate with his or her body language?
- What seemed most important to the interviewee as evidenced by his or her message and surroundings (including clothes)?

When an assistant, who understood the importance of confidentiality, was not transcribing the tapes, they were carefully stored in my home office. I read and reread the transcripts to ensure the most accurate interpretation.

As suggested by Kirby and McKenna (1989), I set up master files to organize the following data produced:

1. Identity of participants, including all demographic and contact information and consent forms
2. Interview tapes
3. Original transcripts (to keep a clean master copy)
4. Field notes
5. Research process notes
6. Written analysis of the transcripts
7. Researcher's journal (on paper and on computer)
8. Literature.

I printed each transcript on different-coloured paper. Along with line numbering, the colour created an easy tracking pattern for each participant. The interview code and colour were glued on each of 11 envelopes, so that any data that did not correspond to a question or emerging category could be easily stored and retrieved from the envelopes.

In order to sort all of the information for presenting to the participants, the questions were pasted onto 4'x3' kraft paper in large print. As categories became evident, they too were posted. Portions of the transcripts were cut up and applied with removable tape under the appropriate heading. Sections that did not fit or were my reiteration of what I thought the person stated went into the envelopes, unless I wanted to clarify the material with the participants. Recognizing that it would take far too long to read out everything on these large pages, I made large print summaries based on the major points I had first highlighted. These summaries retained the participants' own words.

The first step in the data analysis consisted of presenting a summary of the raw data collected to the participants, not only for their clarification and verification, but also for their input on emerging themes and categories.

Study Conduct

This section describes how the participants were determined and the process by which they contributed to the outcomes.

Introductory Luncheon

The questionnaire was introduced at the luncheon held in the Haisla Health Centre on August 25, 2003. All Kitamaat Village residents known to have Type 2 diabetes (approximately 55) were invited, along with their significant others for an added sense of community and support (see Appendix D – Luncheon Invitation). A total of 19 people attended, including 4 health centre staff, 2 who were relatives of attending diabetics, and 2 who were diabetic themselves, and a Type 1 diabetic who attended with their concerned parent.

To honour traditional food, we served a stew commonly served at feasts, made by the CHR, plus three types of bannock – rye, whole wheat, and oatmeal – demonstrating that healthy eating does not necessitate eliminating all familiar foods. In sharing responsibility for the food, the CHR made the rye (buns) and I baked the whole wheat and oatmeal bannock. (See Appendix E – Oatmeal Bannock.) Assorted fruit was offered for dessert, along with an abundance of good humour.

I was pleased that one elder said the opening grace and that another offered the return thanks at the end of the meal. The warm feelings in the room were palpable, and laughter was heard frequently.

At the end of the luncheon, I thanked the CHR for all her hard work, and gave out the last of the door prizes (diabetes care bags and sugar-free food samples). I also showed my poster presentation from Royal Roads University's second Residence, so they could see the research project as a work in progress, with an emphasis on whole health, not just on diabetes. I expressed how important their individual experiences were in helping me and others, as health care providers, know how best to help them and future generations.

Finally, I explained that all participants who were interviewed would be invited to a tea where their responses would be presented to them as a group, with no names used and with only the CHR and me present. The purpose of this second gathering was to clarify how accurately the transcripts reflected their thoughts and feelings. At this time, they would also be encouraged to identify themes or categories that they saw emerging.

The Interviews

The CHR phoned all of the residents who had attended the lunch to confirm their interview participation. Of the 11 people interviewed, only 8 had attended the introductory luncheon. The CHR arranged all interviews: 9 held in the health centre, 1 in the home of an adult caregiver, and 1 in my hospital office. The average age of participants, excluding the Type 1 juvenile diabetic, was 66 years.

No participant requested the tape recorder to be turned off at any point during the interview. I turned it off, though, when the questions had been answered and the conversation turned to other issues. Some of the interviews ended up in two parts: the formalized questionnaire and the informal discussion that followed. Both parts were valuable. However, only the former was transcribed; much of the latter was captured in my process and research log, with accompanying reflections.

The interview that was the most informative was held in the home of the participant's adult daughter, a grandmother herself. Many family photos of different generations decorated the nicely furnished home. A great-grandchild sat in another room watching TV, eating some "Cheezies," and occasionally coming over to us in the dining room to ask her grandmother a question. The opportunity to interview the participant, the great grandmother, in her family's home, with family members sitting around the dining-room table, greatly contributed to the conviviality and the learning.

In contrast, the interview held in my hospital office, which was the most convenient location for the participant, prompted the most stilted conversation. The soft-spoken client was difficult to hear at the best of times, and almost impossible to tape-record. I deduced that the professional setting contributed to her ill ease, although I have no experience with her in another setting. I was reminded of MacKeracher (1996), who insightfully described silence as a way of knowing: Silence is the experience of having no voice, of feeling mindless and voiceless and of being subject to the whims of external authority (p. 139). Of all the participants, this one was likely the most ill-suited to having a meaningful conversation in an office. Not having the CHR present probably made matters worse. Sometimes, the CHR was able to share with me some of the participants' history.

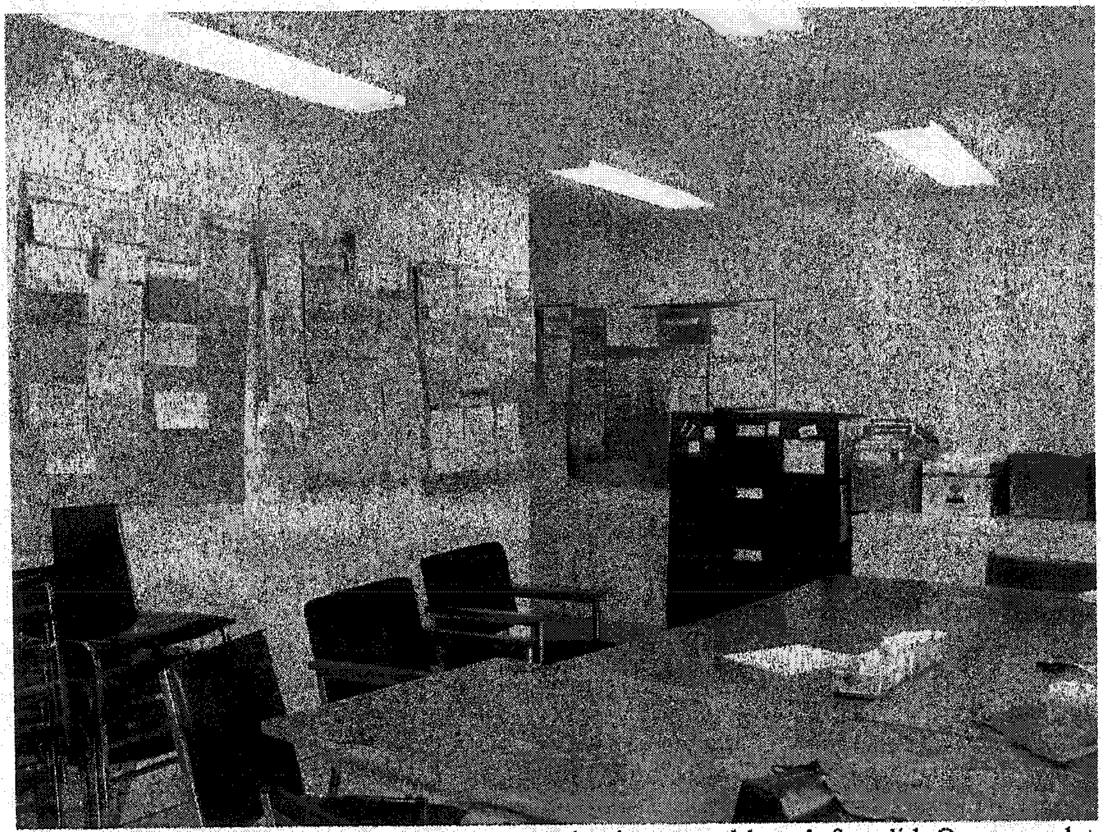
Contrary to my plan, debriefing with the CHR after each interview she attended was not always possible because of her busy schedule. When she was available, I checked if her interpretation of the interview correlated with mine or if she had anything to add. I did not anticipate how involved the CHR would become with these interviews. Her interest in diabetes escalated to the point that she was almost interrupting the interview process with enthusiastic questions and comments. I did not mind at all, as I recognized how her responsiveness could help put the interviewee at ease and result in the surfacing of information and history that would not have otherwise been discussed. One such piece of information concerned the tradition of tying a beaver paw around the wrist of an infant to bring the child dexterity and handicraft skills. If left on too long, however, the child would inherit the beaver's bad temper. These fond recollections seemed to nourish our spirits, and I felt privileged to be included in them.

I intentionally postponed rereading the chapter on "Preparing for Analysis" from Kirby and McKenna (1989), as I wished to keep my mental deliberations separate from the initial data I presented to the participants.

Summary Presentation

The summary presentation was made on November 3, 2003, in the same room as the original luncheon, which provided a sense of familiarity for our group. The participants were invited with a thank-you card, printed on card-stock in colour, so that should they be unable to attend, they would know how much I valued their input (see Appendix F – Participant Thank-you/Invitation). Health centre staff helped me post the kraft paper collages on the walls, so that anyone could read what was actually said (see Figure 4).

Figure 4. Posters on the Haisla Health Centre Boardroom Walls for the November 3, 2003 Summary Presentation



I allowed time for the six who attended to browse, although few did. One came late and then left early for an important church meeting. The participants seemed to prefer to simply listen to me present the summaries. Only a couple of clarifying questions were asked, but they did want copies of the written summaries. I was reluctant to distribute any copies, as I wanted to ensure that only participants read the information. So I gave a summary to the Diabetes Coordinator to loan to any interested interviewee.

Then we served tea and the apple crisp, a low-fat, high-fibre, sugar-reduced version, which had baked in the adjoining kitchen during the session (see Appendix G – Recipe for Apple Crisp). The CHR had done a marvellous job of collecting more door prizes to add to the $60 running shoe gift certificate donated by a glucometer company. She drew names for the door prizes while we finished our refreshments. I followed by presenting thank-you gifts to the CHR, RN, and LPN who had done so much to pull this project together. Then I wondered if I also ought to have given something to the health centre administrator, but I wanted to avoid appearing as though I was influencing her with gifts. As it turned out, she won a beautiful door prize that perfectly suited the family member she was representing.

At first I was surprised and somewhat disappointed that the participants suggested no new themes and did not ask probing questions. I subsequently realized that I was assessing the situation through my lens, where I would have made inquiries, if only to indicate interest. Unlike me, the participants were more comfortable going away with the information and thinking about it before providing feedback. They did discuss specific health promotion strategies that were repeatedly mentioned as desirable. Perhaps they were already looking for tangible results, whereas I still wanted to delve into the intangible and the underlying commonalities.

Follow-Up Phone Calls

I phoned each participant who was unable to attend the summary presentation, letting them know that their input was valued and that should they wish to review the summary comments, they could, through the diabetes coordinator. I received no direct feedback about the interviews or the project; however, two participants had health issues they briefly discussed. In fact, one interviewee's admittance to the hospital resulted in my speaking with his wife, to promote dietary changes.

Data Confirmation and Reporting

I read over the raw data repeatedly to develop categories and themes, which I had hoped would have been identified by the Haisla. Then I compared my findings and observations with pertinent literature to validate my analysis, confirming my expectations, reflecting on potential blind spots, and keeping mindful of the potential need to re-categorize. Trustworthiness of data interpretation was established through peer audit, by consulting with nutritionists and others who have worked extensively with other Aboriginal groups.

This information was then summarized and presented to the health centre staff and the hospital diabetes educator at the Haisla Health Centre on January 21, 2004. Information about effective First Nations diabetes programs elsewhere in Canada was briefly presented, to generate discussion and direction. I then summarized the results in my final report, including my recommendations. This report will be sent to the Haisla health centre administrator, the hospital Diabetes Education Program manager, the COO of the Northwest Health Services Delivery Area (my sponsor), and the NHA Aboriginal Health Services Plan director.

Conclusion

This chapter has reviewed how the research was conducted, analyzed, and presented. In chapter 4, I detail the results of the research, including conclusions and recommendations derived from all participants.

CHAPTER FOUR – RESEARCH RESULTS

This chapter summarizes what I learned from the 11 residents interviewed. They shared their own experience with diabetes and that of their families, as well as their history and culture. They discussed their contact with the health-care system, how it impacted them and what gaps they thought existed. Finally, along with the Haisla health centre staff, the residents suggested how they could be better helped. In this chapter, I present the Haisla's perceptions of diabetes as shaped by various aspects of their culture; an overview of diabetes treatment in Kitamaat Village – present practice, what is required, and the gaps between the two; and my conclusions and recommendations on improving the health of those with diabetes in Kitamaat Village.

Study Findings

Each culture has its own views of what constitutes health and disease. In this section, I examine the Haisla view of diabetes and the types of treatment obtained by the participants.

Haisla Culture as Related to Diabetes

Beliefs.

In many Aboriginal health guides, the Medicine Wheel is used to illustrate whole health by caring about the four aspects of life: physical, emotional, spiritual, and mental. In the Medicine Wheel, fear is addressed in the mental and emotional quadrants through acknowledging and identifying feelings, and learning self-management (National Aboriginal Diabetes Association, 2003). The Haisla, however, do not commonly use the Medicine Wheel (Haisla RN, personal communication, August 14, 2003); hence alternative ways of addressing mental health and emotional issues must be considered. The Haisla RN, who has diabetes, shared with me how other life events contributed to her learning how to best manage her disease. She realized that she needed to change her thinking in order for her actions to hold true; a negative focus would result in self-defeating actions, a positive mental focus, in empowerment.

For other participants, diabetes was shrouded in mystery. There was a perception that the disease took over the body. "But if you keep it in check, take your pills, insulin at the required times, you're keeping it quiet within you. If you get it mad, then it could cripple you. Even the doctors can't explain it yet, to my satisfaction anyway." The condition was regularly referred to as something numeric or outside of the body – for example, "keeping things level," referring to blood sugar. Possibly this expression was an adaptation of medical jargon.

Faith in a greater power was frequently mentioned. "All the time I'm diabetic, I take it seriously. … Maybe it's been that feeling that's kept me going this far, that I have someone … reaching down, blessing me." Faith is a way of displacing fear, as described by one gentleman, who said he felt concerned rather than afraid: " 'That,' I heard a voice saying, 'You don't worry about that. That's for people who don't take care of their sickness.' Then the doctor gave me all the talks, the pills, diabetic pills and … when I should take them. It still hasn't bothered me, to fall victim to that sickness. It must be about 30 years now, that I have it." He was able to openly accept and follow medical treatment protocols.

Another participant who had undergone a near-death experience expressed an intense spirituality. After detailing what he had experienced, I inquired if he felt fear. "No, I'm ready," he calmly replied. This acceptance was evident in another resident, who declared, "Why should I worry when my time is measured?" Their faith was nurtured by "taking part in prayer and in singing," particularly enjoyed by some elders. Many of them had attended residential schools, learned the doctrine of the United Church, and have continued practicing this religion, some with great commitment. A very supportive relationship exists between the church and the community.

Values.

A sense of humour regularly crept into our conversations. On hearing he had diabetes, one resident asked his doctor, “How deadly is this thing?” The doctor replied that some people live 30 years with the condition, to which the resident retorted, with a chuckle, “That’s too damn long.” Despite that instance of profanity, manners are valued.

In fact, being polite may override the need to look after one’s health. As an elder expressed, “I know that if I said ‘No, thank you [to a piece of birthday cake],’ I would be offending the person that’s having a birthday. It’s very difficult for me to say ‘No, thank you, dear.’… I feel that I should accept the dessert that’s being offered to me.” Showing respect for the efforts of others was also demonstrated at our introductory luncheon.

The challenge of adherence to a “diabetic” diet was described as “now, I’m brave and I know what I’m not supposed to have.” It does require courage to preserve dignity while being different, whether it involves living with an obvious physical affliction, sticking to a healthy diet, or living with a mental illness. Given the participant’s age, I wondered if the feeling of being brave referred to coming to terms with the disease, or in fact with death itself. In any case, she valued honest discussion.

When discussing the merits of a particularly good doctor, one participant emphasized the doctor’s honesty: “He would tell you what was happening inside you. … I’ll take all of these things that I gather from doctors very seriously.” He believed his doctor would tell him all he needed to know. This participant also had strong spiritual beliefs, which may have influenced his notions around healing.

In addition to being loyal to doctors (when one moved to Australia, a couple of residents expressed that they missed him), participants also valued other health-care professionals' long-term relationships with them. The Diabetes Education Program (DEP) nurse was frequently referred to. Once respondent described how "I always pay attention to what [the DEP nurse] is drilling into me. I think a lot of her because of her willingness to take time." The Haisla treasure time spent with others.

When asked why she had not been walking with her friend this year, another resident shared, "Her dad isn't healthy any more so she's spending a lot of time with him. I don't want to bother her." Family connections and honouring family commitments are significant mores, perhaps more evident in small, tightly knit, isolated communities.

Finally, compassion was obvious. After the initial 2 weeks of diabetes education in Vancouver, the parent of a diabetic child most remembered "what she must go through. 'Cause when they were teaching us, my husband and I had to do the needle parts, and they started off with an orange first and then they made us do it to each other, give each other shots. So that really stood out, there. It was, I don't know … what she was feeling and she has to have it twice a day." The compassion in her voice was unmistakable, the empathy only felt by a parent for their child.

On the other hand, a participant commented on a lack of compassion demonstrated by a family member. "He doesn't care what he says to me. He says it anyways even if he knows that he's embarrassing me." Families can be hurtful.

Family Connectedness.

However, there was evidence of much family support, parents for their diabetic child, grown children for their diabetic parents, and siblings for each other. Demonstrating a prevalent sense of humour, one participant spoke of his sisters' care: "They treat me as if today is my last day [chuckle]." He added that his sons do the cooking and "the older one, he likes to cook with spices and I hate that sometimes." This comment points to the importance of including family members in diabetes and other health instruction, not only where children are the concern.

One child was included in this study because the mother wished to be involved. This family demonstrated the importance of family support in their shifting of family eating habits to those desired for optimum diabetes care. "Yeah, our eating habits have changed. We usually try to schedule our snacking times around hers, is one thing. We don't just grab something like we used to. We just do it around her schedule, her mealtime schedule." Diabetes care can mean a healthier lifestyle for the entire family.

Accommodating the needs of adult diabetics was less evident. Feasts are a normal part of community or family gatherings, whether they congregate to welcome a guest speaker or to mourn a deceased loved one. Unfortunately for those tempted to overeat, providing excess amounts of food is a traditional practice. Large amounts of high-carbohydrate foods such as juices (sometimes unsweetened) and fruit were served at the same meal, in addition to buns and other refined starch choices. These foods can be part of a healthy diet, but for the diabetic, eating them in combination overloads the body's capacity to maintain normal blood sugar levels. Leftovers represent abundance, to be shared among the most needy, distributed to homebound elders, or given for guests to enjoy at home.

Family ties and knowing about family history were deemed important, particularly in relation to health conditions. Residents recognized that diabetes was not a new disease among them, that it dated back generations. An elder shared with the community health representative

(CHR), in Haisla, that "we probably had this years ago but we didn't know what it was." Another resident said he heard a Kitamaat elder say that when he was young, maybe three generations ago, they recognized when there was too much sugar in the blood, although they did not name it.

Most knew some of their family's health history; five participants stated their mother had diabetes and others mentioned a father, a grandparent, and two nieces or nephews. A genetic predisposition to heart disease was indicated, with one resident stating her mother had heart disease, another participant saying their father had it, and another, an aunt or uncle. Six stated they had heart disease and/or were on cholesterol-lowering drugs. In addition to heart disease accompanying their diabetes, three also spoke of having arthritis. These numbers are not conclusive but are reflective of the prevalence of these diseases among the Haisla.

The impact of family history extends to individuals concerned about their own likelihood of developing the disease. One participant talked about his adult children: "When they wonder what's wrong with them, they ask to get tested for diabetes." Memories of historical diabetic diagnosis and treatment still linger. One resident remembered the doctor in Vancouver telling his mother, " 'The only way you'll combat this is to have a bag of candies in your pocket for when you're feeling lightheaded.'... Insulin was already out but nobody gave it to Mother so she died a young woman, 68 or 69." Another participant recalled his shock upon hearing his diagnosis of diabetes, recalling the words of his mother who lived with it, "In the early years, the way it was diagnosed was if your finger tips or your toes or something was cut off, that was one of the ways that they diagnosed diabetes." They remembered their parents' experience of living with the disease. This intergenerational passing of knowledge transmits both undesirable memories and cherished customs.

The community values learning through doing, as has been the traditional way of learning, in addition to oral history. The CHR spoke about the learning and teaching opportunities in her women's group:

> Our first project was lasagna, which I wasn't good at, so I got recipes. Our next one was making homemade candy. So we got [an elder] in to give directions for that. She was so glad to get out and be among the younger group, so they learned candy making from her and she's got a lot of arts and crafts. Knitting, crocheting, you know.

Utilizing the wisdom and experience of elders contributes to their sense of purpose, and for the residents with whom they interact, a way of looking toward the future while remaining grounded by knowing their past.

Language.

According to the CHR (personal communication, September 8, 2003), the closest Haisla word to "diabetes" means "sick." She was not sure that "heart" and "spirit" were different words in Haisla, and as for the term "blood sugar," it was non-existent.

Residents also rarely used "blood sugar" when they spoke English. I wondered if by not specifying the words, such as "injecting the insulin" or "testing blood sugar," clients were distancing themselves from the disease, as in this parental description of a dialogue: "[The team nurse] was questioning if [the child] was checking herself and we said no she isn't. … But at school she'll do it. She stays at lunchtime."

The vague, unspecific use of nouns came as no surprise, given that Haisla is more of a verb-based language. Another example was, when asked what other information he would like, a participant replied, "How much say a lemon pie is to a doughnut or whatever, you know.

How sweet is it? What can you do, eat in lieu of that?" instead of asking about the *amount* of sugar in foods.

Another illustration of a verb orientation is the resident who clearly recalled the cardiac surgeon's (my supposition) explanation of the process he was due to undergo:

> " 'Well, this vein,' he said, 'collapsed. It has shrunk down quite a bit and it's having a hard time pushing through the blood. Now this is where this is going to go, to keep it open so it doesn't collapse any more.' "

The resident recalled the details of the process; however, professional titles or equipment names seemed unimportant. The verbs "shrunk down, pushing, keep it open, collapse," which describe actions, were given prominence, an important principle for health-care educators to incorporate in teaching.

While respondents rarely remembered the name of the professional doing the instruction or their designation, location of the teaching was always recalled. We all do not value the same details or value them in the same way. One resident remembered seeing a Nuu Chah Nulth band diabetes teaching video at the health centre in Spring 2003. She did not use the common term "boardroom." Instead, she described watching it "in the Circle here," indicating the greater meaning she felt the room held.

A First Nations health professional may have difficulty saying words such as "endocrinologist"; however, the Haisla RN knew how to bridge the knowledge/language gap. Citing her explanation of diabetes, she tells residents, "You're fermenting your body if it has high levels of sugar. What it is, is it's causing damage to your heart, your organs. … It affects your whole system." The residents understand fermentation, as it is a traditional preservation technique they use for preserving salmon eggs and fish-heads. They could picture the degradation of the tissues and how they might look, and relate this to what is happening in their body.

Communication Styles.

Vague references to specific activities or people involved left me questioning my interpretation of some residents' statements. For example, blood glucose monitoring is a very specific practice, and when asked about frequency of testing, one participant stated, "I am willing to keep it in check daily." However, this same person had previously stated, "I take things as they come along now." Was this complacency or acceptance? As health-care professionals, we may accept a client's complacency, rather than encourage them in more healthy practices, out of well-intended respect, unfamiliarity with their background, or language difficulties. Furthermore, we may be unaware of when we are doing so.

Many of the participants were more soft-spoken than people to whom I most commonly listen. I found that by consciously relaxing more, rather than straining to hear, I was able to hear most of the responses. With one participant who was particularly difficult to hear, I realized that I had used only verbal communication. Had I offered her the use of photos or models to express herself, or suggested that she write her responses, our conversation may have been more effective.

Traditional Treatment.

Informants disclosed no information about any traditional medicines used. They did, however, mention many non-Haisla remedies, from "Strauss Heart Drops" obtained from a Kamloops herbalist, to Japanese therapeutic massage. One resident talked about his father who, while living in Vancouver, was hospitalized with a stroke and then told he had only a short time to live. The participant described how his father received alternate therapy:

> Went to Steveston to say goodbye to his Japanese friends and he told them what the doctor said. A Japanese [man] said, "I'm going to fix you." He went and grabbed his head and started massaging his neck. And he was 71 [years of age] and after going to this Japanese doctor and lived until he was 93 … what he did, he opened up his blood vein. There was a clog in there.

This response indicates openness, not only in the flow of blood, but also to alternative medical treatments.

Traditional remedies and even traditional foods seem not to be readily available. For the community of Kitamaat Village, traditional plants other than berries are not easily obtained, nor are salmon and shellfish for those without boats. "Fish is not always that plentiful … unless somebody kindly drops a piece of fish off. … Economy has a lot to do with how we eat." In addition, many low-income shoppers purchase easy-to-prepare foods, such as wieners and boxed macaroni and cheese, which offer little nutritional value for the money, and poorly control satiety and blood sugars.

Diabetes Treatment Received by Kitamaat Village Residents

Current Treatment.

Presently, residents see their doctor "in town" (Kitimat), who then refers them to the Diabetes Education Program (DEP) in Kitimat General Hospital and Health Centre for individualized instruction and follow-up visits by both the diabetes nurse educator and the dietitian. Prior to their initial orientation to diabetes at the "Basic Education Day," residents receive an invitation package that gives them basic information about diabetes and asks them to fill out a lifestyle and history questionnaire. The format of the Basic Education Day is primarily a lecture, with some experiential teaching such as grocery store tours and walking breaks. Revisions are being examined to include more interactive learning.

Individual and group follow-up ensures clients understand their role in managing their diabetes and addresses any challenges and concerns they may have. Either the doctor or the client arranges their individual appointments, following the initial group education sessions, ideally at intervals of 3 months, 6 months, and then on an annual basis once blood sugars are under control.

Residents mentioned going to similar in-patient programs at St. Paul's, Vancouver General, BC Children's, and Prince Rupert hospitals, with the option to receive follow-up support at the local DEP.

Required Treatment.

Treatment must address both the physical and the emotional aspects of diabetes. Current clinical practice guidelines include parameters for lab work, physical activity, and nutrition and drug therapy, all specific to the type of diabetes. Particularly relevant to the residents with whom I spoke are the most recent clinical practice guidelines (Canadian Diabetes Association Clinical Practice Guidelines Expert Committee, 2003), which state that, "individuals with diabetes should be regularly screened for psychological problems, depression and anxiety disorders…[including] questioning about stress, social support, beliefs about their disease and behaviour that could impair glycemic control" (p. 51). Effective communication with all health-care providers, family physicians, nurses and psychologists to name a few, will give the residents their best opportunity to be self-directed. If the resident so chooses, traditional healing methods could then be most successfully incorporated.

Gaps in Treatment Identified by Residents.

The residents expressed unresolved feelings of anger, fear, anxiety, self-judgment, shame, grief, and guilt. They were confused about financial assistance, medical instructions, medications, risk factors, and their prognosis. Finally, they expressed concerns about accessing medical treatment from a remote area.

Inadequate Emotional Support

Despite all the information she received, one resident expressed that her emotional needs were not met. She saw a psychologist because "I felt really down and depressed. … This seems to be controlling my life. … When your mind, when your body is swimming in these high blood sugar levels, it affects your emotional, your mind." This loss of control over one's life resulting from living with a chronic disease is described by Lorig et al. (2000) as

> Having to rely on medications to ease symptoms, having to see a doctor on a regular basis, having to count on others to help you perform daily activities. … Your life has suddenly become a team sport in which you are no longer the coach. (p. 52)

Poor mental attitude alone can be debilitating.

Another loss of control expressed was anger management: "I wasn't in very good shape when I found out I was diabetic because I was … flying off the handle because of your, how you feel. Your emotions start getting you down." Extreme irritability further emphasizes the "power" of the disease.

Some expressed "I was scared," at any point from when they were initially diagnosed to how they viewed the future. Participants were concerned about the possible complications arising from diabetes, the need to cope with concurrent diseases, and the numerous medications for treating them: “I’ve thought of people who have died from diabetes, of heart disease or kidney failure.” Fear was expressed of the unknown, as well as the known.

One resident was very fearful about the possibility of having to inject herself with insulin. Her dread of self-injection was so extreme that only health-care professionals, on a less frequent basis than desirable, could perform blood glucose monitoring. Infrequent testing increases the likelihood of complications. Family members were also concerned about the potential for blindness, kidney disease, heart disease, and amputation.

A parent voiced her fears, “that as she grows older, that she doesn’t take care of herself … not eating the right foods and not eating … that she may get tired of it and not want to take insulin and stuff like that.” Worry on the part of the caregiver(s) places an additional emotional load on the family.

Stress, from a variety of sources ranging from school to relationships, contributed to poor diabetes self-management:

> I guess what I turned to was food, you know, under stress. I studied … so after a couple of my exams, I got 84 or 89. I was very unhappy with that because I was averaging in the 90’s. And so I had to think about … I knew I had to get the diabetic sugars under control.

This was a high achiever struggling to manage stress.

Emotional stress increases blood sugars just as does physical trauma or illness. Needing to eat differently from the rest of the household can be stressful. When other family members snack, “It drives me crazy ‘cause I know now that I can’t eat. I know I can have a certain little snack at 10 o’clock before I go to bed but that’s hard for me too.” Changing dietary habits in addition to simply hearing the diagnosis of diabetes promoted anxiety for both the diabetic and his or her family members.

When participants judged their actions, a sense of being good or bad, rather than proactive or complacent, was prevalent, as the following comment illustrates: "Well, when I eat, I know it's not good for me but I just eat a little bit...what's not good for me." Reducing this sense of good and bad by replacing the terms with choice, such as healthy and less healthy, gives the client a feeling of control, not judgment. One participant who had been in prison might still struggle with this dichotomy. Shame stopped residents from taking action.

One participant's self-awareness was accompanied by self-deprecation. "[As I] got more understanding of what the disease is all about ... I realized the implications of how serious this is and how stupid I've been over the last while ... you know, not to watch myself." Clients may become overwhelmed by a sense of failure.

Another participant talked about the denial and shame associated with being diabetic in the community. In our interview, she recognized she was suppressing her denial when she admitted, "I realized I am a diabetic and there is no denying it anymore. It's tough; it's really tough." This participant was able to express personal rather than "community" feelings, a step forward toward self-empowerment.

Another expressed grief over the loss of the previous way of life: "Once you have diabetes, there is no way of getting better." One participant who had seen a psychologist found the psychologist's individual focus helpful in achieving balance in her life. "I know it's a healthy way of life, good nutrition, exercise, but there's the other side where I feel tired of it like I could ... insulin every day ... plus the glucometer." Until she achieved acceptance of the imposition of diabetes and the perceived loss of freedom, she vacillated between feelings of anger, denial, and fear, leading to guilt over her poor compliance.

Guilt was also expressed over ignorance about how to prevent diabetes or its complications: "I probably wasn't paying attention, not thinking that this would happen to us." Ignorance can be addressed through increased information from health-care professionals. Guilt reduction, however, requires self-knowledge learned through peers, as "often we learn best from people like ourselves, who have experienced what we have gone through" (chronic disease self-management course trainer, personal communication, November 21, 2003). The following comment caused me to question whether diabetes education programs adequately address guilt: "I was devastated and could I have done more to prevent it? … I was trying to treat it as flu." Some participants had achieved acceptance, whereas others continued to be despondent, denying the reality of their condition.

At the time of the interviews, there was no ongoing group support available. Most participants thought that peer discussion, sharing how each other felt, was important and not just knowledge acquisition. A resident expressed concern about the credentials of the person guiding the support. Confidentiality has been overlooked in the past, which can be a painful experience, particularly in a small community.

Unclear Communication With Medical Staff

Residents expressed concerns about the financial burden of diabetes, particularly when combined with misinformation. One resident bought $350 insoles from a visiting foot "doctor" after her own family doctor did not treat her leg pain to her satisfaction. Apparently, her physician did not tell her that there was a local podiatrist who visited Kitamaat Village regularly and whose services were paid for by Medical Services Branch, Health Canada. The responsibility for providing this information lies with numerous health providers, not solely with the family physician. Misinformation about services and personal responsibility extended to other medical conditions too.

One participant developed a collapsed vein to the heart and was part of a prospective cardiology study. He wondered about his diet and wanted "to know how much the other research project affects what you should be doing around diabetes." Another participant had numerous blockages in some arteries to his heart: "Three blockages, one [artery] was 20%, one was 30%, and one is 100% [blocked]." He too had questions about his care. Apparently, these residents' questions were not heard or worded in such a way as to elicit the replies they needed from their doctors.

On the other hand, some doctors were excellent communicators. One man carefully recalled his doctor's explanation of renal threshold:

> I listened to everything that the doctor told me and I learned later on I could be … what you call damming your system. … I listened to that quite well because I kind of thought that was going to be one of the key things to remember. The doctor told me that the higher the dam, the higher your blood sugar goes before it goes into the urine. Some people might have about 140 and I was showing 290, I think it was, before it starts showing trace; it affects me this way as well.

This detailed recollection demonstrates that when a doctor or other respected health-care provider takes the time to explain the condition, the particulars can be clearly remembered.

When health-care workers use vague terms, they add to the complacency and confusion of the clients. One resident was told by his doctor to "take it easy with the salt … [and] the sugar." "Borderline" was a term used by doctors to describe slightly elevated blood sugars in a random blood test. Residents reported their doctor telling them that "I just have to be careful. 'You are not really a diabetic.' " They specifically stated their doctor's words – for example, " 'You're just what we call borderline, not bad,' he said, 'but not good either.' "

This vague term "borderline" was frequently mentioned, often as a reason to ignore taking action to prevent diabetic complications: "I sort of pushed it to the back of my mind and I ignored it." Surprisingly, Tessier (2003), a medical doctor, deemed that colloquial terms such as "a touch of diabetes" or "borderline diabetes" are sometimes invoked to justify minimal intervention and to hypothesize that vascular problems are likely unrelated to the metabolic abnormality (p. 3). Apparently, when a doctor is unsure of the etiology (cause) of slightly elevated blood sugars, the patient need not take preventive measures to avoid making the situation worse.

The doctor's disregard of patient empowerment is particularly obvious when prescribing medications. Confusion over multiple medications was common, expressed by three of the participants afflicted with combined heart disease, diabetes, and arthritis. One did not know exactly when to take her medication and why. Another complained about the side effects from trying two lipid-lowering drugs. I was asked how the heart pills affect blood sugars. One asked me, "To have a good heart, [blood sugar] has to be between three and seven maybe?" The relationship between heart health and blood sugar was frequently questioned. Another resident stated that her doctor "didn't tell me what she put me on. [The doctor] didn't tell me and I asked the pharmacist. He was the one that told me what they were for." Confusion, in addition to the disease symptoms, is distressing for these people and reduces their ability to cope.

Diabetic control requires regular finger-prick blood tests. Some residents stated they never or rarely tested themselves; one stated he tested four times a day. Some were told to check their blood sugar three to four times per day, another only twice a week. The differing recommendations clearly need individualized explanations. For example, the resident who said she needed to test only twice a week requires the understanding that if her consistently normal blood sugars changed, she would have to increase her glucose self-monitoring.

Remote Location

Living in Kitamaat Village or Kitimat necessitates frequent travel to Vancouver to receive specialized medical treatment, whether for the parents of a newly diagnosed diabetic child needing education or a middle-aged resident requiring the specialized diagnostic equipment unavailable in northern BC. In addition to the burden of the disease itself, this travelling imposes a load on the patients and their families. One elder described having to wait at Vancouver's airport for 6 to 7 hours before his flight departed for Terrace/Kitimat Airport. Owing to poor weather, the one and a half-hour flight was rerouted to Prince Rupert, resulting in an additional 4-hour bus trip to reach home. This 12-hour journey occurred after being discharged a day early following prostate surgery.

At the same time, there are fewer health professionals in the northern half of the province from whom to choose, further limiting the choice of care. The consequences of living in a remote location were mentioned. "My mother … she lived down the Channel … so she didn't see the doctor right away." The participant wondered if the disease had progressed significantly prior to the diagnosis.

Risk Factor Awareness.

A lack of awareness of factors contributing to heart disease was common among participants, despite their known medical history. Two residents surmised there was a link between past heart problems and current diabetes. When I informed a participant that smoking was a risk factor, her response amid laughter was "that's, that's really funny. My doctor has never, ever, ever mentioned it to me." Another resident said she was unaware that proper shoes were needed for walking, despite having foot and leg pains.

Some residents indicated they had little or no recent information about diabetes. A surprising comment came from someone who a number of years ago attempted to attend the local DEP, but no one was at the scheduled time and place. Another recalled that in Prince Rupert "I went to three or four [classes] … it wasn't really organized … in 1994, spring of '94." This vague recollection of instruction received long ago was echoed in other sentiments: "Yes, in Vancouver … in the late seventies, early eighties … for a week. I think it was St. Paul's." These clients may be unaware of important health information.

Failure to recognize the symptoms delays diagnosis and treatment, and increases the risk of complications and the likelihood of insulin injections being required. Symptoms experienced by participants prior to their diagnosis of diabetes included irritability, extreme thirst, fatigue, blurred vision, dizziness, repeated yeast infections, and frequent urination. Despite the availability of many posters and public awareness campaigns to address these warning signs, the participants expressed they would have liked more information about the symptoms.

Health-care professionals with diabetes are not immune to ignoring symptoms, consciously or unconsciously. "I was thirsty, [had] classic symptoms … my knowledge of diabetes was limited to my training as a nurse." This respondent found it difficult to personally apply the information she had learned. On being informed about her diagnosis, she stated,

> I was not devastated by the news. As I said, I had some knowledge about diabetes. … I treated it as not a big deal, that I could manage it, whereas if *you* got it [blood sugar reading over 27], I'd be calling 911.

Health-care professionals may also underestimate the seriousness of their condition in order to cope.

When asked their initial thoughts on learning their diagnosis, participants commented: "I wanted to sleep all the time"; "I'd get really tired even by washing dishes, just standing there"; "I was drinking a lot, a lot of water"; "I had what he called 'fruity breath' "; and "I kept getting yeast infections." They described the physical symptoms of diabetes, not their thoughts; their symptoms precipitated their diagnosis.

Diagnosis time varied according to symptoms. Some experienced symptoms severe enough to cause immediate hospitalization and confirmation of diabetes; others had vague symptoms experienced over months, even years, where recurrent physician visits were involved. Infection was present in four of the residents, alerting the doctors to test for diabetes. One was post-surgery and two respondents complained of recurrent yeast infections. In addition to diabetes, two residents had extensive food allergies (nuts, cow's milk, processed meats, and cheese), which added to their medical challenges and those of their families. The many symptoms of diabetes make conveying its risks and symptoms a complex task, with huge amounts of written information developed to describe the diabetic experience.

One participant commented that he had received many brochures, which he still possessed many years later although he did not read them. According to the CHR, another resident had some difficulty filling out the consent form. Although some participants had an excellent command of English, others had more difficulty, indicating a range of educational backgrounds. It remains unclear whether or not written information and diet poster guidelines were helpful.

Study Conclusions

Definite areas of support are needed, for the individual with diabetes, for their families, for the health-care workers who regularly see them, for the physicians who treat them, and for the band council, to demonstrate best practice health care. Trained, trusted personnel are essential for a successful program.

Family Support

The whole family is affected when a member is diagnosed with a chronic disease. The parent of a diabetic child stated that hearing from other parents and children in the same situation would be helpful, to address her concerns and those of her child:

> There are times when she does get frustrated. … [The child said] she wished she didn't have it, but not very often. Just a few times she's said that, just blurted it out … she's just quite shy and doesn't talk to anybody.

Currently, a group for families with a child living with diabetes is available only in Terrace, an hour's drive away.

Family members may not understand, because they do not know what the diabetic is experiencing. One participant woefully stated, about driving to Terrace, "The one thing I couldn't get across to my children is that I'm weaker than I look. And this is tiring for me; they see these trips as they would … they don't realize what is happening within me." Often with chronic diseases, the victim is so involved with what they are experiencing that they fail to see how they need to specify their limitations and their needs. On the other hand, family members must be aware of the limits, listen carefully, and seek creative alternatives.

One participant mentioned a past program involving "little group sessions, just diabetics and a family member, the spouse or son or daughter, so that they could better understand what you're going through. That should be something that we should bring back." His recollection of this program illustrates its value to this person, helping both the family and the individual.

In addition to support groups for children and other family members, a group for elders was requested, to encourage increased physical activity, for "learning how to cook properly" and for helping to prevent "slipping back into the same old age habits." Many participants requested a time for interviewees to share after the research, to hear what each other had said and to learn from each other.

An elder expressed, "Just going out for an hour is very, very important for an eighty year old person [even if it meant] getting out of [our] beds and our comfortable chairs." The rewards outweigh the discomfort: "We forget about taking our medicine … it takes my mind off my pains, to get out." Even specific timing was recommended: "It's very difficult for me to sit for one hour … it could be in the afternoon when you have whatever you plan on having, because it's difficult for us to get out after supper." Another expressed, "Whatever, as long as it isn't a whole day." For seniors, a full day's session is too long; I recall a senior falling asleep after lunch, during my talk about eating at restaurants.

Individual Support

Individual consultations were deemed important, in addition to the group sessions. Visits to the local hospital diabetes nurse educator were particularly significant, with one participant stating that she was "the one person that has really, really helped me to get through all of this. … [The diabetes nurse educator] keeps on top of things like the other medications that I'm taking, she paid attention to my lab work." The individual attention was appreciated and effective, particularly as part of an interdisciplinary approach.

Managing psychological stress is only briefly discussed in the local Diabetes Education Program owing to the lack of personnel and time, not the failure to recognize its significance. Personal issues such as how to promote nurturing relationships are vital in treating physical diseases such as diabetes. Perhaps self-management support groups would address ongoing emotional needs as well as or better than one-on-one professional appointments.

Site.

Regarding the location of instruction, the village was definitely preferred by participants. If the meetings were held in the hospital, "nobody will go … because they can't get over there, transportation-wise." Taxi service is expensive and many residents do not have the use of a vehicle. The hospital staff is willing to go to the village, but medical care will continue to be provided mainly at the hospital.

Instructional Content.

Participants mentioned several areas of content that would be important to include in teaching sessions, whether formal or informal. Informal teaching, particularly cooking, was remembered best. "About 12 or more so years, in G. F. Strong [Rehabilitation Centre]… they had luncheons, where you learned … what to cook and what not to have, you know." This same person commented on how much she enjoyed our introductory lunch and "getting together with others." Another stated, "Along with diabetes, I have high cholesterol." The message we convey about diabetes is best remembered as part of a practical experience and must address maintaining normal lipid (cholesterol) levels and glycemic (blood glucose) control.

Surprisingly, even if the class they attended was 5 to 10 years ago, some residents thought that was sufficient. Given that 3 of the 11 interviewees could remember only the location of the class, the long-term impact was negligible. "I went through the whole thing ...four or five years ago," and "I went to [the diabetes nurse educator] ... in the old hospital before they moved out," over 2 years ago. Given the poor recall of the important information presented, there is a need for more affective teaching that touches the emotions of learners, not just knowledge transfer, which only impacts cognition. As symptoms were defined experientially and not cognitively, it follows that for teaching tools to be most meaningful for the client, they need to be visual or tactile.

Videos were mentioned, covering complications and exercise programs showing how to gradually increase activity for seniors. One participant regularly watched *Health Matters* on television, an American program that addresses topics such as "heart problems." Health professionals need a greater awareness of what televised health information is available and how to best incorporate this information into their teaching.

Diet.

Conclusive data pertaining to diet centered on the consumption of few fruits and more so, vegetables. Few traditional foods were mentioned other than salmon, eulachon and eulachon grease. According to the Haisla health centre staff, traditional foods include kelp, water fowl, pheasant, seal and seafood such as crab, clams, cockles, mussels, shrimp and prawns, sea cucumber and, "years ago" before being on the endangered list, abalone (Haisla staff, personal communication, January 21, 2004). The result is a diet generally high in fat, of all types and low in fibre.

Activity.

On several occasions, we discussed the value of increased activity of any type, not just exercise. The CHR was ready to enlist people into the walking program right at the interviews or sessions I attended. Furthermore, participants recognized that their weight was a determinant of their health and their diabetes management, demonstrated by the following comment: "I think I need to lose weight … not eat as much as I used to … walk." When asked if she knew that her weight would make her diabetes worse, the participant replied, "Definitely." Other than basketball and walking, few recreation opportunities exist for adults in Kitamaat Village.

Ensuring Follow-Up.

Without follow-up assessments, lifestyle changes cannot be assured or monitored. As a resident expressed, "I think for the person who has no nursing background, the amount of information is overwhelming." Instruction over a few days or even a few weeks is rarely adequate to allow assimilation of new concepts, particularly for a chronic disease. Another stated, "At first I tried going to the dietitian … started eating good … but stopped." Unfortunately when clients lapse in their progress, many avoid follow-up. Regular support offered to the residents by the Diabetes Education Program (DEP) is poorly utilized.

Previously, Pharmacare required a yearly visit to the local DEP to obtain a certificate for subsidized or free test strips. Now, with the discontinuation of the certification program, these yearly follow-ups are the responsibility of the client or a re-referral from their doctor. Years can pass without a client receiving updated information; however, the DEP is looking at alternatives for maintaining closer client contact (diabetes nurse educator, personal communication, January 21, 2004).

Communication Styles.

I realized in an attempt to be efficient, I am likely to use *my* most comfortable communication style, instead of suggesting alternatives to clients for communicating in a manner of their choosing. Potentially, I have overlooked a wealth of information they might have divulged in an unexpected manner that, in the long term, might result in far more effective, individually focused care.

Cross-cultural teaching involves much more exchange at a deeper level than words and intonation. It requires adapting information to the learner. Written information may need to be set at a lower reading level. Also, words may not be the best format for clear communication.

Empowerment and Self-Determination.

Courage is admired, but what people usually need is empowerment. Courage is entirely self-originating, whereas empowerment involves others' support and motivation, with or without their knowing. For example, her grandson motivated one participant: "Five years ago, my incentive was my grandson, to take him for a walk. I feel I could take him around the block and gradually we'd explore, go further and further and further." As a health professional, she understood the importance of empowerment by helping others find meaningful incentives. She said, "So, it's working with the person, exploring what would work for them…to say 'What do I need to work on?' to take baby steps." Self-determination develops the character and courage to contend not only with a chronic disease, but also with all types of challenges that life presents.

Involvement in research studies provides a type of support, although an ambivalent one. One participant included in a research study figured he was "not invited to these classes because I'm on this experiment thing." I could not assess whether he was not provided with clear information or whether he misinterpreted the information he received. He did indicate he was interested in attending a diabetes class.

Supporting the Health-Care Worker with Diabetes.

The two health-care workers interviewed admitted they required support for programs they wished to implement, for their professional development, and for their own health. One said that when she was struggling with her own lifestyle choices, she felt less effective in working with diabetic clients. "I have done everything that I can to try and get people interested in just getting out walking … and it's just not happening." She did mention that once she began her own walking program, others joined her.

In addition to the responsibility experienced as a role model, a health-care worker's additional knowledge may promote greater fear of the disease. One nurse stated, "I know the side effects. There's heart disease, there's kidney function and most of all, mental health." She added that in hospital, as a patient, being a nurse is also not an advantage: "When I go somewhere, I don't tell them I'm a nurse. Sometimes it's the doctor that tells them that and I say no, I'm not a nurse [laughter] because they assume … we don't know everything." She wanted to be treated just like anyone else diagnosed with diabetes, not as a health-care professional, with hospital staff assuming that she already knew all she needed. Health-care professionals may particularly benefit from a chronic disease self-management (CDSM) course, to help apply the information to how they live their lives, not just to remember the facts.

Governance and Health

Band Council.

The professional development of health centre staff was expressed as a concern. One employee stated, "Our band has had no money to send me away to do any training at all." However, the NHA director of Aboriginal Services (personal communication, January 16, 2004) reassured me that the bands all received specific government funding for nurses' continuing education. I learned later, though, that band councils have the final decision over allocation of money according to band needs. Inconsistencies between information sources are common.

Health status documentation, particularly when done by the First Nations communities themselves, may be difficult for non-residents to obtain. The information belongs to the band and requires band council approval in order for it to be released. Therefore, the Health Portfolio representatives (elected by the band) on council first need assurance about exactly how the information will be used, what the merits of releasing the study(s) are, and to whom it may be shown. Only once the Health Portfolio representatives are convinced of an issue's importance will it be brought to the full council for approval.

Provincial Support.

University-supported programs contribute significantly to First Nations community health. The residents valued the travelling Retinopathy Clinic sponsored by the University of British Columbia, where they were examined and instructed on eye-related concerns, in addition to overall diabetes care, including that of the feet. One participant explained, "She was a doctor or a nurse. Anyway, she told me to take my shoes off to check my feet. It wasn't in front of everybody and she was really pleased with my feet … cause it's dangerous when you're a diabetic, how even your toenails are … have to cut them." In addition to the residents appreciating this private consultation, the occasion provided an opportunity for the hospital diabetes education staff to connect with both the residents and the travelling clinicians, allowing them to promote the local program's follow-up services.

Federal Support.

Health Canada must continue its funding initiatives and assistance for residents' medical travel. However some residents perceived Health Canada as being insensitive and uninformed about the realities of living in a remote coastal community, setting inflexible rules about length of stay and accommodation for medical trips. A desire on the government's part to learn more about the situation was not apparent, as illustrated by one participant's comments:

> They want to argue with you and I try to give my reasons for wanting to stay a little longer because it takes me awhile to get rested up to travel. They don't understand this. I've had the phone, I've had them hang up on me twice.

In an earlier comment, he stated, "To me, we're human beings, like everybody else. You know, we should be treated the same." If he meant feeling discriminated against on account of his First Nations heritage, he did not clarify this. He reasonably expected a Health Canada representative to listen to his concerns.

The band council can be caught in the middle as they administer the federal programs and must follow federal policies to receive continued funding. The health centre administration expressed that the residents think the health centre is reducing monetary support, whereas in fact less money is a direct result of federal cutbacks (M. Nyce, personal communication, January 21, 2004).

In addition to assisting with medical travel costs, federal funding also supports community health representatives. The local CHR was instrumental in organizing the interviews. She was very enthusiastic, asked many questions about diabetes for her own family's benefit, and was interested in the historical foundations of chronic disease in Kitamaat Village. Her experience and background of growing up in the village gave her credibility rarely achieved by a non-resident.

Collaborative Medical Support

Support for health-care professionals on reserve or those who work with First Nations communities is inadequate. An "us and them" mentality causes assumptions to be drawn and leaves both sides wondering about the other's protocol, expectations, disillusionment, and successes. When First Nations and non-Aboriginal health-care workers work together more closely, these perceived boundaries can disappear, resulting in improved worker satisfaction, a reduced sense of isolation, and subsequently the improved health of clients.

Non-Aboriginal health-care providers may see a client's health-care practices and overlook the impact of family relations, the influence of culture, and the client's definition of health. We may avoid asking critical questions for fear of offending the client and yet we do both parties an injustice by not daring to seek answers. Health-care professionals need to feel more comfortable about stating what they do not know and how the client might help them to understand. Finally, as summarized by Graziani, Rosenthal and Diamond (1999), physicians should avoid minimizing diabetes to their patients and help their patients reduce their fear and denial related to diabetes by addressing these issues when they are identified (p. 362). Health-care professionals must meet the client at their level of need or readiness.

According to a Haisla health-care professional, a diabetic needs to be taught in the following manner: "The first step is to know what their blood sugar is. The next step is to gradually work with a client for nutrition, and to gradually start them out, small steps for exercise." Simple; maybe that is what we are missing.

Study Recommendations

Overall, residents have indicated that a more holistic approach to diabetes care and prevention is needed, one that includes the entire family. More interactive approaches to teaching will improve knowledge retention and application. Mental and emotional health issues require additional support, much of which may be provided by a trained peer-led group. Health-care professionals, working more closely together, will need to incorporate feedback from the clients and adopt new teaching approaches, in order to sustain the positive changes required.

Client Support

Include family members in diabetes instruction, as lifestyle changes in activity, eating habits, and handling of emotions are best accomplished with family involvement. In addition, intergenerational teaching reinforces healthy living for all ages.

Disseminating information may be less important than creating a supportive environment for attempting change. Demonstrating activities at each session enables participants to feel the positive benefits they can derive from making small changes to their lifestyle. Providing a small amount of information at frequent intervals is preferable to daylong sporadic sessions. Sessions for elders should be 1 to 2 hours maximum. All clients appreciate the choice of both individual professional follow-up and group support where they can share with their peers.

Initiate a chronic disease self-management (CDSM) course. Support from others reduces the sense of isolation that so often accompanies the chronic disease experience. Coping with the feelings associated with having a chronic disease is essential in order for long-term self-management to take place (Lorig et al., 2000). Learning from peers, both the clients with the disease and their significant others, is most effective when the group has a proven format to follow, as in CDSM programs. In these 6-week sessions, individuals share how they overcome challenges in all areas, physical, emotional, mental, and spiritual. As described in the *Living a Healthy Life With Chronic Conditions: Self-Management Course, Leader's Manual*, lay people with chronic conditions, when given a detailed leader's manual, can teach CDSM as effectively as, if not more effectively than, health professionals (Lorig, Gonzalez, & Laurent, 1999, p. i).

Given the history of experiential learning used by the Haisla, creative, interactive teaching methods will be most effective. Diabetes jeopardy, nutrition bingo, nutrition "twister" for able participants, and other instructional games create a lighthearted atmosphere that promotes trust and sharing of deeper concerns that eventually need to be expressed in order for whole health to result. Small-group activities such as planning a trip or a menu, creating a garden or a meal, and elders teaching children about health, can contribute to the self-direction and self-confidence that empower both the individual and the community.

Help residents become proactive, expert patients who know their needs, rights, responsibilities, and resources. When residents learn the best way to express and define their needs, they can assist health-care providers in better fulfilling their roles. CDSM programs emphasize the importance of solving problems by examining the options and making short-term action plans that clients feel confident they can accomplish. The key is to improve their self-efficacy, a sense of what they are capable of achieving.

We must focus on helping residents learn how to pose questions to medical staff. Residents were confused by inconsistent information given to them by their doctors and other health-care professionals. Clear communication is a shared responsibility.

A healthy, economical menu created jointly by the residents and a dietitian may be the most powerful teaching tool, showing how healthy eating does not have to be more expensive or less appealing. The incorporation of rituals (sharing food, initiating a project with a prayer, or giving symbolic gifts), as suggested by Tripp-Reimer et al. (2001) may also aid in establishing an effective milieu (Summary of Effective Cultural Interventions, 3rd last para). We must venture beyond just sharing food if we wish to create enduring bonds.

Construction of a walkway to honour family members will increase resident activity both in its construction and in its use. People unable to walk need professional encouragement to try other movement such as seated exercises. Because a physical behavioural change is required, verbal discussion and cognitive knowledge have far less impact than visual, experiential teaching through participant involvement. People need to experience that an activity feels good. Community input on how they can increase physical activity will add to program success and long-term results. A community gym/recreation building is needed.

Support healthy lifestyle teaching as part of the school curriculum. Recently, a breakfast program has been re-instituted 3 mornings per week (diabetes coordinator, personal conversation, January 7, 2004). The involvement of a dietitian is beneficial for monitoring, for example, the overuse of juice instead of water for fulfilling hydration needs.

A brief list of travel tips needs to be understood by all diabetics and their families. One insulin-dependent participant, who usually performs blood sugar tests 4 times a day, found that travelling diverted his attention from his routine. "So I pretty much pay attention to that [testing blood sugars] but yesterday, I totally forgot about my daughter needing my truck so I was not prepared to do things. That's what happens when I travel sometimes. It's travelling that really begins to show I have to monitor." Given the travelling by car, boat, and plane that these residents must do, knowledge about maintaining normal blood sugars when travelling is important.

Fostering Follow-Up.

Health-care professionals who adopt a more proactive, supportive approach to for example, missed appointments (instead of labelling clients as non-compliant), find a follow-up phone call to the person often reveals important related issues. Additionally, incorporating Haisla values such as family, fun, and food would encourage attendance. Initial information could be reinforced by presenting it in various ways over several months, with participants awarded a certificate of completion at the end of the "course." In health care, we can easily overlook the importance of recognizing and rewarding our clients for their efforts.

Use of Media.

To increase health professionals' awareness of public health information programs, a Web site could be created for health-related television programs. On entering the topic for example, diabetes, a listing of relevant shows would appear, along with the times and channels where they would air. This use of existing media instruction would help to reduce the cost of resources purchased by health-care institutions and agencies.

A pamphlet outlining the services and programs offered by the hospital would be useful to staff, physicians, and the public. In addition, a pamphlet would save each department having to develop its own program promotional materials, and the content could be incorporated into a hospital or Kitimat Valley Health Web site. Health-related programs available in the village could also be included.

Physicians need better handout information for clients to follow until the allied health professional is available. The Canadian Diabetes Association's "Just the Basics" tear-off sheet can be easily given out by physicians when they newly diagnose diabetes. By doctors clarifying the resources they need to nurses and dietitians, for example, these health-care professionals can ensure that the best information is provided for the physicians' offices.

To better educate the public about diabetes, more diagrammatic "signs and symptoms" materials must be available. Given that diabetics have double the risk of cardiovascular disease in comparison to non-diabetics, and in First Nations, three times the rate of heart problems and hypertension, according to *Diabetes in Canada* (Health Canada, 2003a), clearer communication of risk factors is needed. Health professionals may be diluting their message by handing out too much information at once; our message may be clearer with one or two handouts per contact. In addition, waiting areas might be considered as places to view health information videos, not just written information.

Support by Health-care Professionals

Greater involvement of professional counselors may be needed to overcome issues around shame, not necessarily resulting from residential school experiences or abuse, but the shame of diabetes. Recently, at a conference, an elder shared how because of diabetes he could no longer make love to his wife, despite having fathered six children. He also shared his embarrassment over being unable to control his anger at an important meeting, and his remorse over being undisciplined where food was concerned. Shame and guilt contribute to the anger that prevents acceptance of the condition. A referral to the psychologist accompanying each diagnosis of diabetes fulfills best practice guidelines and may dramatically enhance the client's quality of life.

More discussion around grief and the stages involved in acceptance of diabetes is necessary, as many of the residents expressed the following emotions:

> Otherwise, we can become "stuck" in one or more stages (e.g., resignation, or vacillating between anger and denial).
>
> **S**hock – numbness, confusion, disorientation
>
> **A**nger and/or depression ([anger] directed inward) – sadness, fear
>
> **R**ejection – including denial of emotional impact
>
> **A**cceptance or resignation (hopeless "acceptance")
>
> **H**ope – positive focus on the future

The acronym SARAH simplifies the stages through one must progress. (SARAH Stages of Grief, 2001, 3rd article)

Greater involvement by pharmacists in education will help both the clients and those who work with the clients. Pharmacists have the most in-depth and up-to-date medication information on individuals, and their service is highly regarded by the residents. An innovative way of including the pharmacy would be a regular question-and-answer time for people with diabetes, or perhaps a newsletter or Web site geared to local concerns.

In a more complex, holistic approach, health-care providers need to work closely together to ensure that roles are well defined and that everyone, including the client, knows each other's abilities and expectations and can locate the desired help. Regardless of the availability of funds, community collaboration between village staff and their Kitimat colleagues will enhance capacity building and professional development. Accompanying clients (with their permission) to educational sessions could also help fine-tune instructions and teaching styles for all the health professionals involved, particularly if team teaching was supported. Teaching about diabetes prevention in the village is best done jointly, headed up by both RNs, ideally both being certified diabetes educators. An invitation to all Kitimat education programs should be extended to all residents who wish to attend. Car-pooling may be an option for those without a vehicle.

Regular visits by city clinicians to rural clinics, particularly for some complex cases, would support and inform local health-care professionals, in addition to sparing that particular patient the hardship of another trip to Vancouver. The urban clinician would gain awareness of the specific community and personal challenges faced by both practitioners and patients, comparable to the type of information gained about a patient in a home visit compared with an office visit.

In addition, provincial diabetes education programs could work more closely together to minimize client travel and maximize local experience and support. Improved communication via patient care plans, detailing what the patient had learned, as well as their goals and challenges, in a folder the client controlled, would sustain comprehensive support from training hospital to rural location. Local care providers' questions regarding optimum follow-up could be quickly answered by including a specific name and phone number or e-mail address for the urban diabetes educator. The result would be decreased travel costs for families and professionals, as well as a more informed local care provider. An unanswered question is whether the Vancouver program funding is based on referral numbers, thereby reducing the incentive to provide more local support.

The hospital could act as a communications base where the visiting team could either meet with the local physicians or leave paper copies of referral letters. Two physicians considered that they did not receive timely reports from the visiting retinopathy clinic, resulting in double referrals to the ophthalmologist.

A 24-hour diabetes hotline, similar to Cancer Connect, might reduce the sense of isolation felt by patients on returning home. Also, closely examining the connections between the urban medical services and remote location follow-up would determine how the most effective, least costly gaps could be filled.

Better use of videoconferencing to link with an endocrinologist in St. Paul's Hospital could provide a specialist's services without the client necessarily having to go to Vancouver.

Contacting diabetes researchers who use sophisticated screening tools for detecting complications such as nephropathy (kidney disease), neuropathy (nerve damage), retinopathy (eye damage), and cardiovascular disease, would improve care. These tools can be used even in remote communities (Hanley et al., 2003).

Ongoing Medication Review and Explanation

Improving the partnership between home nursing, the pharmacy, and the physician might help to reduce medication error and misuse. The use of blister-packed pills would be helpful in reducing medication error and in the long run possibly saving time for both the home care nurse and the pharmacist. Ensuring that physicians phone the pharmacy to change medication dosages would promote the most up-to-date records of residents' medications.

Clients must be kept informed of their health, at their level of comprehension, throughout the health support process. Health-care professionals must clarify their own understanding of the client's concerns, and then match the needs of the client with the appropriate type of information source, whether it be via illustration, printed material, video, demonstration, or Web site. Doubts and fear may flourish when health-care providers inform people poorly, either because the material given to clients is overwhelming or they do not understand the explanation given about their condition. Before further teaching can ensue, their fears must be quelled.

Diabetes care providers for all marginalized groups, such as the poor, the elderly, single parents, and those with a poor understanding of English or French, in addition to Aboriginal peoples, must be sensitive to the specific needs of that group. Socio-economic and health statistics provide broad assessment guidelines but are not enough, because we are dealing with individuals who have varied histories. Listening closely to them will give direction to those who listen. Health-care professionals may feel they lack the time, resources, information, and sometimes motivation, according to Tripp-Reimer et al. (2001), [however] they fail to recognize that these are the same reasons offered by patients who have difficulties managing a recommended therapeutic regimen (Barriers to Care, Practitioner Barriers, last para). Change starts with us, within ourselves.

As health supporters, we might consider the body as being part of the entire universal system, rather than as separated from the outside by skin. Instead of giving an impression of deprivation to achieve health, helping clients to focus on their body's needs, treating it as part of nature and nurturing it, is far more in line with Indigenous spirituality.

Band Commitment

The band's support for ongoing training for health-care workers is essential for long-term health improvements. Some excellent teaching aids, such as diabetes teaching vests, are left in the proverbial drawer if health professionals are not trained how to use them. In addition, staff need to meet colleagues who share their concerns and interests, to renew enthusiasm for creating new programs and approaches.

Community health representatives (CHRs), or other cultural brokers, must be in as many patient education programs as possible, as they provide the link between the information and the culture. In his speech on preventing complications such as foot ulceration, and worse, amputation, given at the 3rd National Conference on Diabetes and Aboriginal Peoples earlier this year, Dr. K. V. Ung (2004) spoke about the important role of CHRs and community health nurses (CHNs). When he was asked if he would like two more doctors to help him with his Native reserve work, he responded, "No, I'd rather have two more CHN/CHRs."

The band should consider how they want the health of the community to appear. For example, is a feast a celebration of life and abundance of health for generations to come, or does it promote a disregard for the body and send the wrong message to the children? All citizens should be supported in maintaining health.

Final Analysis

After living with these discussions on paper and in my head, I realize how many of these people's concerns revolve around communication: clear communication with health-care providers including their doctors; concise, understandable communication from health professionals; and residents' comfort in asking for support from family members. According to the village RN, family members are increasingly relied on as "Indian Affairs" loosens its paternalistic hand. "Residents have to be more responsible for themselves" (L. Grant, personal communication, January 29, 2004). As residents learn to ask the right questions, they will become more activate in and informed about maintaining their health and well-being.

In the next chapter, I examine the broader implications of these recommendations at the organizational and the community levels.

CHAPTER FIVE – RESEARCH IMPLICATIONS

In this chapter, I discuss implications of my research findings for the various organizations involved, in terms of the many organizational opportunities that are available as well as the anticipated challenges. I then propose steps toward implementing an integrated health-care system, and finally, I suggest future research opportunities.

Organizational Implications

The Northern Health Authority (NHA) has acknowledged the need to maintain close liaison with First Nations communities. Its Aboriginal Health Services Plan (Patterson, 2003) recognized that Health Canada is not adequately meeting the needs of First Nations communities, mainly because the Health Transfer Policy makes no provision to promote increased First Nations participation in all levels of the Canadian health-care system (Lavoie, 2004, p. 9). In order to improve health-care delivery to Kitamaat Village, for example, strategies are needed that promote collaboration between the federal government (First Nations and Inuit Health Branch [FNIHB]) and the transferred organization, Kitamaat Village. In addition, there is a need to develop community-specific action plans that focus on areas of common interest and opportunities for improving health or health services.

The Aboriginal Health Services Plan (Patterson, 2003) also explicitly described the need for accountability:

- Of Chief and Council to community members
- Of Chief and Council to the Minister of Health to First Nation and Inuit communities
- Of the Minister of Health to First Nation and Inuit communities
- Of the Minister of Health to Parliament (p. 27).

I would add the need for accountability of the NHA to its Aboriginal partners to assist them in accessing available services and making those services as culturally sensitive as possible. This project serves as an example of the NHA's support. Along with other provincially directed, locally implemented initiatives, this study incorporates the following NHA (2003b) priorities aligned with Ministry of Health Services goals:

1. To foster the development of community health centre models of service delivery in smaller communities
2. To implement the three-year primary care plan
3. To develop population health strategy and research capacity
4. To focus on improving internal and external communications
5. To support services redesign
6. To ensure efficient and effective use of limited resources
7. To implement the Aboriginal Health Services Plan for the NHA. (pp. 42-43)

The last point requires more emphasis. An Australian working paper on Aboriginal health recognized that *health services must be provided in a culturally secure environment and manner* (their emphasis) and that health practices need to change in some ways to accommodate legitimate cultural rights, views, values, and expectations of Aboriginal peoples (Western Australian Aboriginal Health Strategy, 2000). The prevailing view of health care must reflect the collaborated values. In addition, the Western Australian Aboriginal Health Strategy (2000) affirmed that service delivery needs to be coordinated within the health-care system – for example, between primary and secondary services (p. 9).

The *Aboriginal Health Services Plan* (Patterson, 2003) described only the general implementation process. Each community must decide how it will bridge the gaps in its particular situation. One thing is for certain: the process will grow best from the grassroots level, not from organizations or governments dictating procedures. The more we invite each other to meetings and involve each other in our educational initiatives, the stronger our ties will be, with the clients/patients benefiting from our increased awareness of each other's protocols and culture. In addition, community health promotion activities will distinguish the identity of the Kitimat Valley as separate from that of the NHA, while still contributing to and being supported by the organization.

Over the past few months, the Kitimat hospital has invited Haisla health centre staff to collaborate in diabetes and heart health initiatives. The health centre in turn has invited hospital staff to help with an upcoming "Hearts @ work" fair directed to both schoolchildren and their parents. A Kitimat interagency group has developed a social plan to encourage health and safety for all families. Together, we are assessing how we can best meet the needs of the residents, in both communities, with shared resources.

Given the dependence of Kitamaat Village on the hospital services, a meeting between the heads of the two facilities will be helpful in clarifying assumptions. The Health Services administrator from the hospital, accompanied by a couple of staff familiar with the Haisla residents, could meet with the Haisla Health Centre administrator and the two Health Portfolio members from the band council. This group could review policies to ensure the best interests of both communities. In Sandy Lake, Ontario, for example, the chief and council formed a partnership with the medical director of the Sioux Lookout Zone that was "built on a shared commitment to long-term solutions and the acknowledgment that each partner contributes unique and critical strengths" (Macaulay et al., 2003, p. 466). With a clearer understanding of the whole picture, health centre administrators could improve access to care for Haisla residents. This demonstration of support from the managers sends a clear message to the front-line staff as to how they may proceed. Input from the community, however, is vital.

In Kahnawake, a Community Advisory Board was formed, and included "volunteers from multiple sectors of the community, who actively participate in all aspects of the project, from design through implementation, data interpretation and dissemination of results" (Macaulay et al., 2003, p. 466). The board-researcher relationship was fostered by jointly creating the Kahnawake Schools Diabetes Prevention Project (KSDPP) Code of Research Ethics prior to the commencement of the project (Kahnawake Schools Diabetes Prevention Project, 2004b). The code attests to the value of clearly defining our ethical positions at the outset of developing community ties.

A key difference between these research situations and our own is that in both the Sandy Lake and Kahnawake instances, the communities' leaders approached the local physicians to develop primary prevention projects. We, on the other hand, are health-care providers seeking to establish effective means to create positive health changes in a group whose intent is less defined. Hence, for successful collaboration to continue, clarifying both our ethical positions and our intentions to each other must be made a priority.

Supportive change must be tangible, in actions and not just in words, although the language we use reflects change. Just as the front desk of a modern hospital is called "reception" or "visitor services" instead of "switchboard," as a result of changes in technology and a focus on making the visitor or patient feel welcome, we need to ensure the use of progressive language. Renaming the facility to "Kitimat Health Centre and General Hospital" would be a start, placing more significance on health promotion and illness prevention.

Our health centre has to demonstrate that it values the citizens it serves by portraying some of their character. An example could be a mural painted by high-school art students to embellish the huge white tube that dissects the entrance to the mall area. First Nations art and other community artworks would celebrate local talent and at the same time create a more pleasant and supportive atmosphere for visitors in what can be emotionally fraught circumstances. In fact, these artistic embellishments are being mounted as this document is being completed.

Another way of enhancing the hospital experience for First Nations visitors would be having an Aboriginal patient liaison worker available to assist Haisla patients and their families. Having their concerns effectively communicated to the health-care professionals and feeling more oriented to the environment might promote a shorter, more positive hospital stay. Regular meetings of Kitimat facility staff with the Haisla health centre staff will ensure the steps they take together are not only in the same direction, but also synchronized, conceivably leading to a higher level of performance, enthusiasm, and conviction than if either had "done it alone."

Challenges

Our geographic position and area create multiple challenges. Physicians require support for using distance-treatment approaches. The absence of a Medical Services Plan code for Telehealth (video-conferencing) services is a financial barrier to physician participation. Careful planning is therefore required to ensure optimum use of this equipment (NHA, 2003b). Doctors need to be compensated for patient consultations, either in their office or via tele- or video-conferencing.

Geography poses a challenge for the director of the NHA Aboriginal Health Services. According to the *Aboriginal Health Services Plan,* the director is responsible and accountable for providing leadership to the planning, coordination, integration, operation, and evaluation of Aboriginal programs, policies, and services throughout the NHA (Patterson, 2003, p. 14). The director has two assistants to help cover the same geographic area (62% of the province) that is covered by the NHA's chief executive officer, three chief operating officers, and a dozen or so health services administrators, all with at least one assistant. Of the approximately 320,000 people living in the area, 13-15% are Aboriginal, the highest proportion in the province (p. 19).

Given that there are 61 Aboriginal communities and 28 municipal-style communities whose health services and needs vary widely, more support for the implementation of the Aboriginal Health Services Plan is required. As pointed out by Maberley (2004), Aboriginal hospitalization and deaths from diabetes are twice the non-Aboriginal rate. In addition, for Status Indians living on reserve, the NHA is required to provide Acute Care, Continuing Care, Public Health, and Environmental Health services (Patterson, 2003, p. 25). Gaps continue to exist because of the people involved and the systems they support.

We need to simplify the processes involved in funding Aboriginal health services by consolidating funding and creating partnerships (Romanow, 2002). In taking a "whole health" approach, we need to define our partners. Based on some potential partners listed in the executive summary of Diabetes in Canada (National Diabetes Strategy Coordinating Committee, 2003), these are the bodies we need to involve:

1. National, provincial, and regional Aboriginal organizations – Promote and develop health policies, supportive communities, and community action.

2. Academia – Provide education for professionals-in-training and continuing education for those working in the field.
3. Researchers – Conduct research on causation, effectiveness of interventions, and health services.
4. Consumers – Develop and maintain personal health practices and healthy lifestyles; increase awareness and participate in community action for a supportive environment; advocate for healthy public places.
5. Governments – Provide comprehensive approaches, ranging from public health policy creation, to program funding and implementation, evaluation, and monitoring across the health, recreation, and education sectors.
6. Private sector – Provide corporate sponsorship, raise awareness, provide workplace programs, and develop products that enhance the lives of individuals with diabetes and their families.
7. Multicultural organizations – Raise awareness among cultural groups and government and other organizations; encourage adoption of healthy lifestyles (pp. 4-5).

Steps Toward Locally Integrated Health-Care Delivery

Kitimat is primed for an integrated approach to health-care redesign, with the introduction of other community collaboratives (on such issues as congestive heart failure and diabetes), its designation as a primary health-care site, the commencement of chronic disease self-management groups and interagency links, and a supportive management philosophy (Northern Health Authority, 2003d). How this integrated approach might look is represented in the Expanded Chronic Care Model, (see Appendix H - Integrating Health Care Services as a

Part of the Community), resulting in informed, activated community members and prepared, proactive practice teams who are also community partners (Barr et al., 2003, p. 77).

The following points, specific to the Kitimat Valley, describe how an integrated, interdisciplinary, community-responsive approach will be sustainable:

1. Ensure that Kitamaat and Kitimat health-care staff attend Aboriginal conferences, regionally, provincially, and locally, which provide valuable sharing and visioning opportunities.
2. Participate in and partner with research activities such as the Kahnawake Schools Diabetes Prevention Project, both for academic training and for sharing how their model is adapted into our communities.
3. Work with all schools, in particular with teachers, to promote activities such as snowshoeing and kayaking experiences, to ensure the availability of nutritious food by assisting parent advisory councils and caterers, and to make healthy living a part of the school curriculum.
4. Work with the District of Kitimat to enhance accessibility to fitness programs and to serve as a recreation resource for the village.
5. Promote the idea among local industries and businesses that "working healthy is working smart." Continue liaison with occupational health nurses in health fairs.
6. Collaboratively pursue grant and funding opportunities for hiring staff, inviting researchers for co-education, and helping purchase equipment for various activities.
7. Work toward developing a community advisory group, as was done in Kahnawake (McComber & McGregor, 2004).

8. Assist Kitamaat Village in utilizing external funding sources such as the Aboriginal Health Initiative Program offered by the NHA (2004).
9. Invite the Haisla health centre administrator to familiarize hospital/health centre staff with the Non-Insured Health Benefits program, administered by First Nations and Inuit Health Branch (FNIHB), and to explain the monetary medical assistance to which most Haisla are entitled.

In the end, it may not be so important what we do but how we do it. The success of our collaborative relationships will depend, according to Lemchuk-Favel and Jock (2004), on the attitudes and open-mindedness of all parties who have put aside jurisdictional differences to work on common solutions to health issues (p. 30). Equally important, as health-care professionals, we must take the time to become knowledgeable about the impact of Canada's history on our Aboriginal people. As emphasized in the *Aboriginal Health Services Plan* (Patterson, 2003),

> Services that are not sensitive to the needs of Aboriginal people – or to new immigrants, the socially or economically disadvantaged, the elderly or women – create invisible barriers to access which waste resources and fail to improve health. In addition to ensuring that all health workers understand these cultural realities, opportunities exist within the primary care model to maximize the scope of and support to indigenous health workers to increase the acceptability and the effectiveness of health services. (p. 4)

Only then can we begin to form partnerships based on trust and not on assumptions. We need to follow this simple Australian tenet: acknowledge and respect Aboriginal people's living culture and find ways of growing with it (Western Australian Aboriginal Health Strategy, 2000). We will all be richer for it.

Future Research

This project has served as a catalyst for building closer working relationships between a First Nations health centre and a non-Aboriginal facility serving First Nations people. It has helped to generate new enthusiasm and awareness in some health-care professionals in both centres. Directing the spread of this enthusiasm according to client needs and wishes, community governance and health provider ability and availability are yet other areas of study. We know that community collaboration is vital, but we are still uncertain about the milestones that guide our path.

Specific to the health status of the Haisla, researching the effect of living in Kitimat compared to living in Kitamaat Village could provide information about detailed practices requiring continuation or change on the part of both the client and the health service providers.

Key indicators must be determined that demonstrate we are achieving the best results, deemed by the clients we serve, not just by the professionals involved. Wallerstein (as cited in Macauley et al., 2003) supported this view by using participatory evaluation models that allow the community to assess their own "indicators of success."

Sharing our results with other integrated health-care centres will create a more complete map in realizing effective diabetes prevention strategies. By contributing to "best practice" sites, researchers can see,

> If there are common key community characteristics and intervention strategies that support these long-term projects. This knowledge will then be used to identify additional Aboriginal communities and to partner with those communities to design

> interventions that incorporate the strengths of both KSDPP and SLHDP [Sandy Lake Health and Diabetes Project]. (Macauley et al., 2003, p. 473)

I hope to write Dr. Macauley to determine if and how we, in the Kitimat Valley, could participate in such a venture. Many partnerships are yet to be defined in this exciting, ongoing project.

We will need support, however, because we are breaking new ground. As stated by Romanow (2002), in many respects, primary health care goes against the grain. It goes against entrenched practices in the prevailing culture of our health-care system, and it sometimes runs into powerful interests and long-standing privileges (p. 119). The British Columbia Medical Association recognizes the challenges, and by investing in a team approach as elaborated at the BC Diabetes Collaborative Conference, Vancouver, BC, March 4-5, 2004, is paving the way for interdisciplinary creative problem solving that puts patients' needs first. Focusing on the clashes of cultures only entrenches us in the past. Alternatively, being flexible and welcoming open dialogue among all parties involved will help us create a health-responsive system.

The next and final chapter is a confessional of how much I have learned, how much unexpected learning occurred, and how I might do research differently in the future.

CHAPTER SIX – LESSONS LEARNED

Research Project Lessons Learned

Big-Picture Learning

Little did I know how much developing this project would influence my thought sequencing. I learned how to tackle a simple idea and expand it into a web of thoughts that, although initially daunting, when categorized could be divided into a series of smaller lessons.

More so, I saw how the iterative nature of research is comparable to the very universe we live in. We start with an inkling of a proposal and the more we focus upon it, through discussion with others and reading, the clearer our thoughts become. But then a point is reached where we see how many variables influence the proposition, and we realize we need to refocus once again. We continue to check our direction through accessing different contemporaries' perspectives that allow us to approach the project from slightly different angles until we see our original idea in a new light. I am this point now, with some resolution of the issues of how to approach diabetes management in a First Nations community, and at the same time, recognition of all that influences health outcomes.

The relationships between the elements of the system, the invisible kaleidoscope, create the critical mass of the project. The stunning photos of our infinitesimally layered universe, courtesy of Parry-Hill, Burdett, and Davidson (2003) from the National High Magnetic Field Laboratory at Florida State University beautifully depicted my learning. The changing photos portrayed how each new discovery elicited a new perspective from which to define the need for the next learning. My assumptions were continuously challenged provided I was open to new ideas. In the end, what I initially assessed as a complex situation may in fact prove to have a solution so simple that it has been overlooked. Could many of our health care dilemmas of today be resolved by simply putting the "care" back into health care? Could the answer lie in respecting everyone's needs and ideas equally - for example, the patient's as much as the doctor's?

I am confident that the answers will emerge. At the same time, I am conscious of when I am thinking too much without allowing, "gaps [to] arise in between thoughts – spaciousness, stillness. You begin to realize how much vaster and deeper you are than your thoughts" (Tolle, 2003, p. 45).

Regarding an attitude shift in the participants, I am not aware of the study having had an impact, although the village RN with whom I worked most closely demonstrated a renewed enthusiasm for her work. In my last conversation with her, she stated she actually was excited about her job. Referring to the overarching goal of this project, to help all parties involved achieve a better understanding of past experiences, present circumstances, and future possibilities, the reactions of the two nurses led me to conclude that this goal has been at least initiated. I also learned what challenges to expect along the way.

Schedule Challenges

Reflecting back on the process of my project, my first "bump" occurred in July 2003, when I was ready to begin but I had no band council resolution (BCR) to formally allow me to start the project. I learned to be prepared to wait and do other constructive activities while waiting. I thought that once I explained the project's importance to the health centre administrator, she might expedite the process. Realistically, my proposal was among other band business items on a council meeting agenda, so it could be bumped to the next meeting quite easily. I was unaware that not only was the signature of the chief required, but also those of other Council members were needed, making a total of eight signatures for the project. Signing the BCR became a priority when it posed the sole stumbling block for the Royal Roads Ethics Review Board approval and when the eager health centre staff, with authorization from the health centre administrator, had begun to arrange the interviews.

The health centre staff could "make or break" a project. Enlisting the help of a reliable, enthusiastic, and supportive staff was critical. It reduced the time I needed to spend on photocopying, delivery of invitations, confirmation phone calls, and food arrangements. Most importantly, the process ensured community sensitivity. Had I not worked closely with the CHR, I would have taken a more impersonal, if more efficient (in my mind) approach by mailing out the invitations. Inviting all residents with diabetes to a luncheon of traditional food was an experience far more enriching for all, even for those diabetics who did not end up being interviewed.

It also took the emphasis off my need to find participants and instead to focus on their needs, that is, the needs of my potential participants. We were able to provide the experience of how healthy eating could be based on their own foods, and a forum to express feelings about diabetes if they chose. I realized too the importance of their meeting me face to face, to become acquainted prior to my interviewing them.

Despite my experience doing individual counselling, the interviews went less smoothly than I had hoped. I ought to have piloted the interview with an actual resident, not just with the CHR and a non-Aboriginal MALT student with diabetes. A pilot with a resident would have helped me to check the questions, as they proved both too long and repetitious.

I would have also been alerted to my interviewing techniques. By listening to the tapes, I recognized that I occasionally thought out loud after asking the questions, which may have served only to confuse the interviewee. I unintentionally asked more than one question at a time, so the participant may have wondered how to respond. I have learned to more often clamp my lips shut after one question. I am much more aware of asking multiple questions without waiting for a response, a common characteristic in many of my peers. It appears not to honour the listener, who is left wondering which answer to give, and it reminds me how I feel when I'm asked a barrage of questions: interrogated. I am now keenly aware of avoiding asking successive questions.

In September, not wanting to turn anyone away, I ended up with 11 interviews instead of 5. Despite the extra work, I would prepare for this number again, largely to honour the participants. I trusted that if they felt the need to share, their words needed to be heard.

I also accepted that as a dietitian, I would be asked many diet-related questions that could affect the smooth flow of the research protocol. Once again, I conceded that the need of the residents for helpful information outweighed my need to follow protocol when relationship building was my focus.

Completing the transcription, however, was a major feat. Taping the interviews posed a challenge owing to the poor quality of the tape recorder, some soft-spoken interviewees, and the varying locations. In hindsight, giving each participant a choice between reading a paragraph or talking about his or her favourite topic could have allowed me to do a sound check. This check would have saved hours of straining to hear and understand the tapes, while also reducing transcription time and costs.

With the combination of my transcriptionist's busy schedule and the large number of interviews, transcription was only completed at the end of October, delaying the presentation to the participants. The CHR and I decided to keep things simple and, rather than another lunch, served a tea and healthy dessert. This was a wise decision, particularly as only 6 of the 11 came, plus the CHR. I learned to have no set expectations and to accept that whatever happened was supposed to be the result. I saw that my detailed planning might have little or no effect on the outcome of our interactions. My undivided attention and awareness were far more important.

In preparation for this presentation, I re-read each transcript completed by the transcriber, so I could correct and fill in gaps she could not understand. I was relieved that my background knowledge about diabetes and health, plus the interview time I spent with each person, significantly added to my comprehension of their words. Much information would have been missed had I not carefully listened to all of the tapes a number of times.

Debriefing with the CHR directly after the interactions was not always possible. Speaking with her several days later was sufficient, to confirm that my phoning the participants who could not attend would be appropriate.

Staff Response

I wasn't prepared for the eagerness of the health centre staff. They wanted to implement walking and support groups and have greater involvement with the hospital programs immediately. I questioned the need for them to hear my project summary and recommendations prior to their implementing any changes. However, on January 21, 2004, when I presented my findings to the health centre administrator, the RN, the CHR, the home support worker, the diabetes coordinators (village and hospital), and others who made brief appearances, it became obvious that they appreciated my assessment of their situation and the words of their residents.

I was pleased with the outcome of this unusual way to present my findings. Instead of a formal presentation, I asked each of the attendees to read, as they felt comfortable, several pages of essentially chapter 4, in font size 14 with different colours for each section. This approach created an atmosphere of storytelling and listening to familiar voices, providing a very effective technique for presenting interview results. Consequently, I think the staff's greater involvement in presenting the material encouraged them to give me grounded feedback to incorporate into my final document. They also provided me with the reassurance that I was addressing the right issues and being adequately sensitive to their culture and their needs. Finally, I was told the results were presented in such a way that they were easily understood. Too often, they said, research is expressed at a level that leaves the participants wondering what was stated, something I consciously attempted to avoid.

Unexpected Outcomes

At this meeting, the two RNs discovered how an unfavourable situation for both of them had come into existence. After the presentation, a brief discussion helped to clarify how the roadblock had been created and which assumptions had further supported it. How rewarding it was for me to see the misunderstanding dissolve and the two of them planning new arrangements. The words of Mealli and Rubin (2002) regarding assumptions and health outcomes summarize how such misunderstandings can occur: "An important lesson is that there are no universally appropriate assumptions. Different scientific settings support different assumptions as appropriate" (para. 1). We can never assume another's understanding.

The last lessons learned were (1) be prepared for anything and (2) whatever happens is supposed to happen. In the Fall, at work, I became very involved with Primary Health Care (PHC) renewal, to the extent that it compromised the time I was able to spend working on my thesis. After a short time, I acknowledged that my passion for PHC could complement, rather than impede, this project, as long as I let go of fears and doubts about time adequacy and just trusted the process.

Sure enough, an even more rewarding challenge was presented to me when an abstract I submitted to the National Aboriginal Diabetes Association (NADA) about finding one's place in a First Nations community was accepted, and I was asked to speak at the association's Vancouver conference at the end of January 2004. Then, after a mid-December interview for the PHC coordinator position, I was offered that full-time job beginning January 5, 2004. It is likely that were it not for this position, I would not have found the funding to attend the NADA conference. Most certainly, I would not have accessed additional funds for enabling the Haisla health centre RN to attend the conference and co-present with me. Our joint participation effectively demonstrated the partnership that is the cornerstone of Primary Health Care, as indicated in our presentation summary (see Appendix I – NADA Presentation Handout).

So, by the end of February, I had not yet completed the deliverable I considered would best demonstrate my learning, a PowerPoint presentation for NHA staff. I know better now. The PowerPoint presentation will come at an appropriate time to the right audience but digital projectors, dimmed lights, and laptop-focused speakers tend to create distance from the audience. The presentation I wish to make will instead take the form of discussion around case studies and storytelling. These techniques illustrate the relationships that foster the process of slowly building bridges through establishing key links of trust. Perhaps through the use of Microsoft Project, I will learn to portray these relationships and summarize each person's roles. How exciting that the learning never ends.

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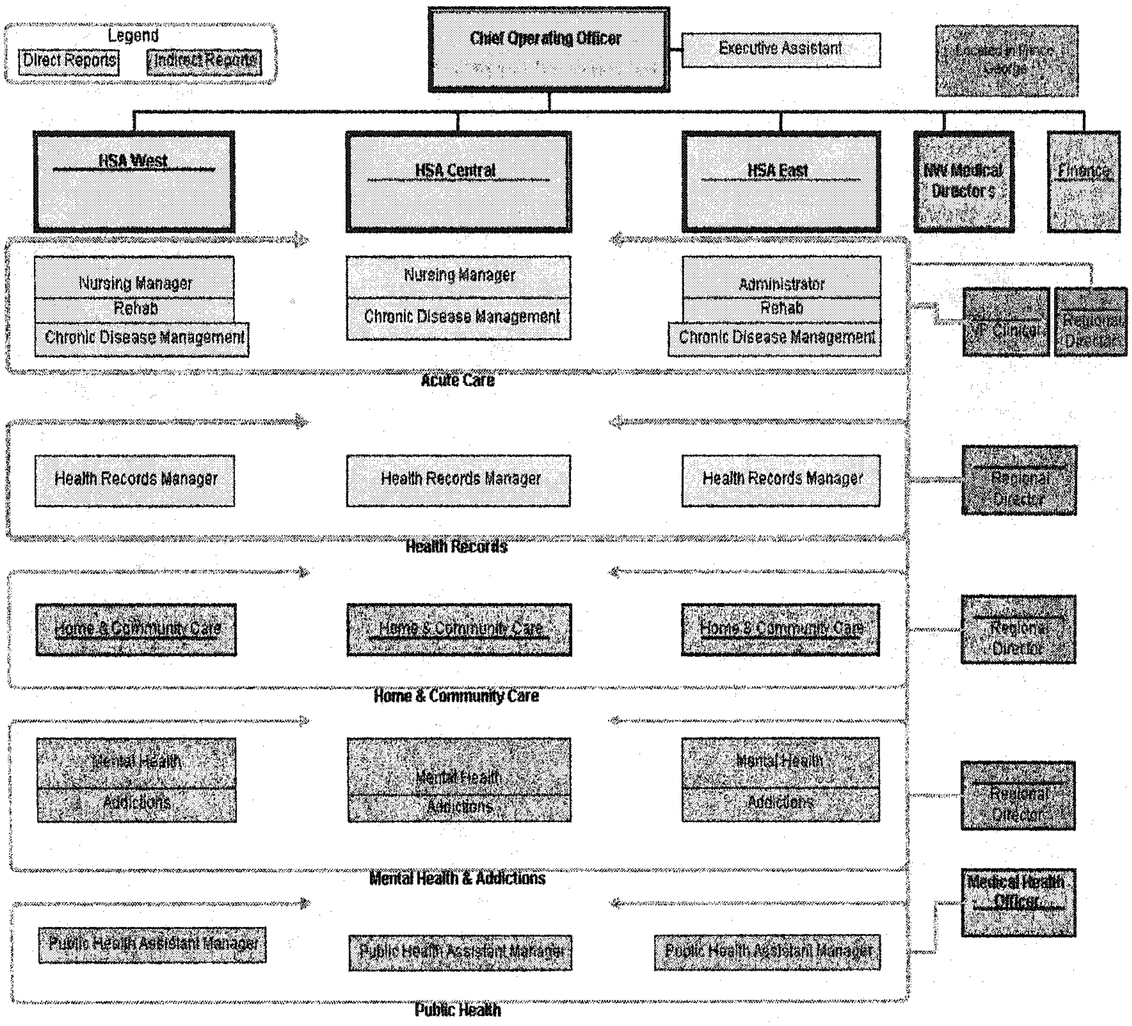
Appendix A:

Appendix A - NW Health Services Delivery Area -Conceptual Organization Chart



Appendix B:

Developing a First Nations Diabetes Program - Royal Roads University
PARTICIPANT CONSENT FORM

I, __________________________, AGREE TO PARTICIPATE IN A RESEARCH PROJECT EXPLORING THE EXPERIENCES AND NEEDS OF RESIDENTS IN KITAMAAT VILLAGE WITH TYPE 2 DIABETES. THIS PROJECT IS CONDUCTED BY A GRADUATE STUDENT AS PART OF THE REQUIREMENTS FOR A MASTER'S DEGREE.

1. I agree to be interviewed by __________________________________under the following conditions:
2. I have the right to withdraw from any activity in this project at any time for any reason. If I choose to do so, the information I provide will be removed from the researchers' files and not used in the project.
3. I agree to an initial single interview that will last approximately one hour and will be tape-recorded.
4. I understand that the interview will be written out and that tapes and transcripts will not be shared with anyone besides the researchers.
5. I agree to notify the Community Health Representative (CHR) in advance if I need to cancel the interview.
6. My identity outside the group of (ten) participants will be kept confidential. Names will be removed and a code will be used in any reports. I understand that the findings may be shared in papers presented to health-promotion meetings or published in healthcare journals.
7. I will not discuss information shared among participants during this project. I will not disclose their identities or involvement in this project to anyone outside the research team and participant group.
8. No deception will be used in this study and participation in this project and I will not be harmed as the result of the research.

I agree to these conditions:

Signed____Date_______________

Researcher
Signed____Date_______________

For further information regarding the purpose and methods of this project, feel free to contact either of the following:
Esther Stevens, Researcher Barbara Spronk, Master's Project Supervisor
(phone numbers/ email addresses)

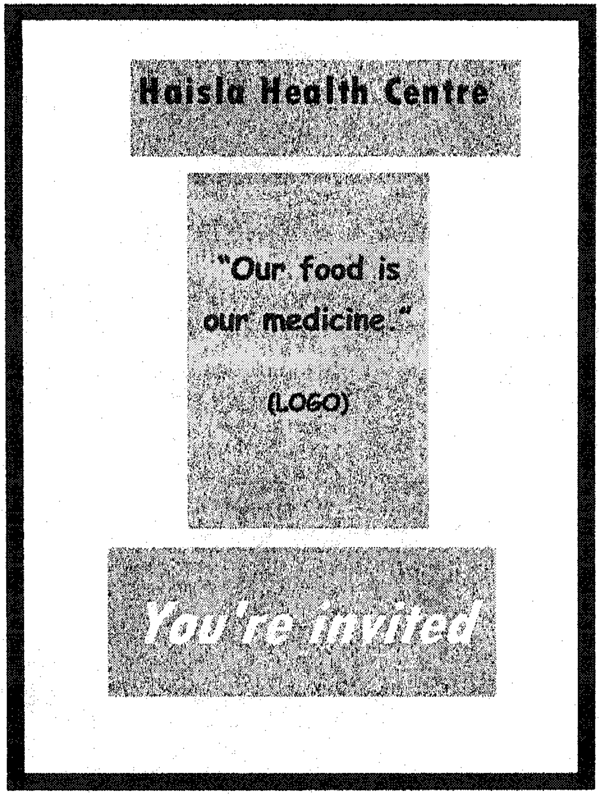
Appendix C:

Questionnaire for Kitamaat Village Residents with Diabetes

1. When you first learned from your doctor that you had diabetes, what thoughts went through your mind?
2. What information or support would have helped you the most at that time?
3. Have you attended a diabetes education class? If so, where?
4. What do you remember learning from the diabetes class?
5. What information or support would help you at this time?
6. What most concerns you about your health?
7. If you could choose any program or support, what would help you the most?

Appendix D:

Luncheon Invitation

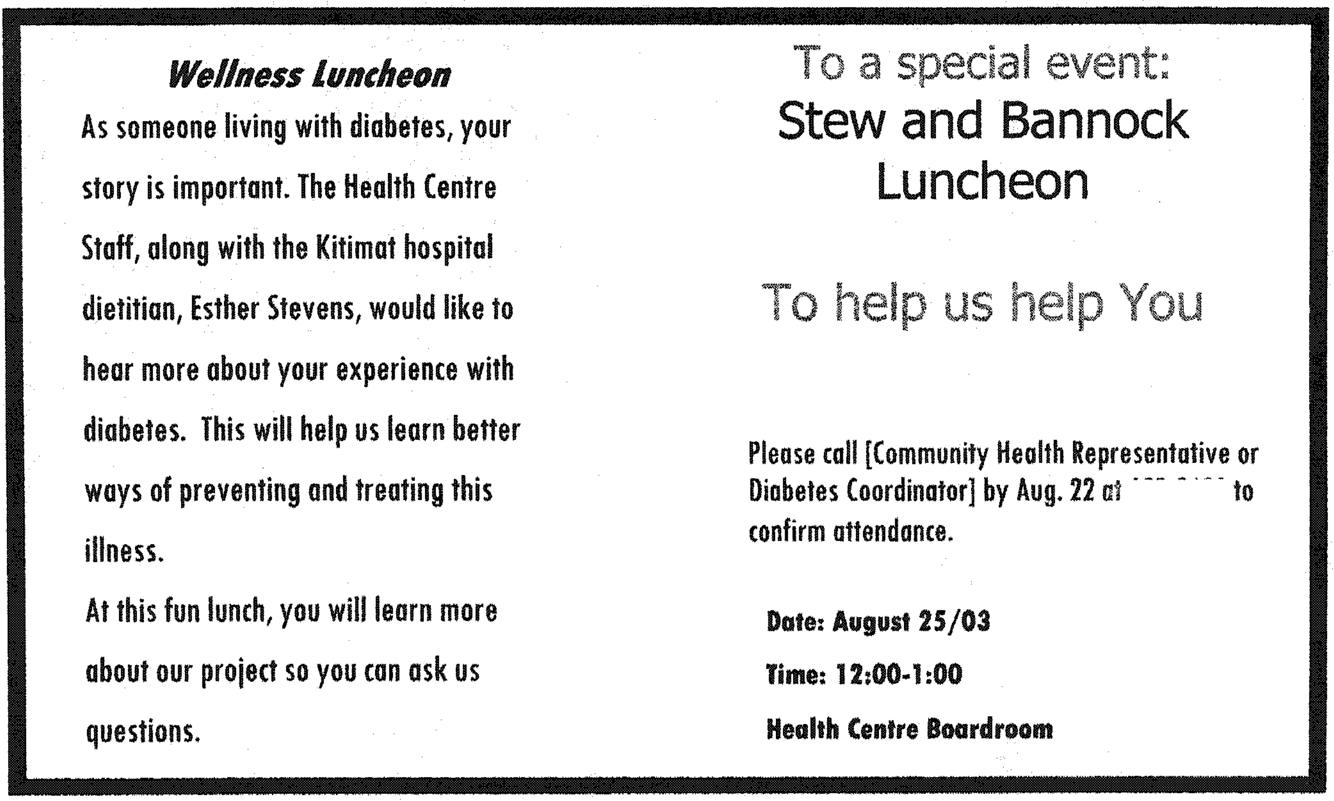


Haisla Health Centre

"Our food is our medicine."

(LOGO)

You're invited



Wellness Luncheon

As someone living with diabetes, your story is important. The Health Centre Staff, along with the Kitimat hospital dietitian, Esther Stevens, would like to hear more about your experience with diabetes. This will help us learn better ways of preventing and treating this illness.

At this fun lunch, you will learn more about our project so you can ask us questions.

To a special event:

Stew and Bannock Luncheon

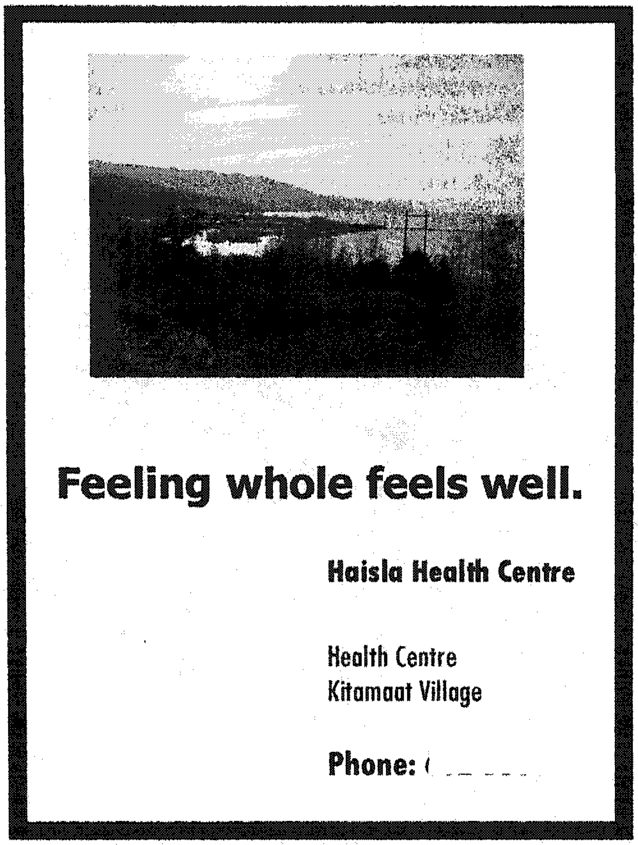
To help us help You

Please call [Community Health Representative or Diabetes Coordinator] by Aug. 22 at [redacted] to confirm attendance.

Date: August 25/03

Time: 12:00-1:00

Health Centre Boardroom



Feeling whole feels well.

Haisla Health Centre

Health Centre
Kitamaat Village

Phone: (

Appendix E

Oatmeal Bannock Makes 50

4 cups unbleached flour
3 Tbsp. baking powder
1 Tbsp. sugar
½ tsp. Salt
1 cup whole wheat flour
2 ½ cups small flake oatmeal
½ cup Canola or sunflower oil
2/3 cup skim milk powder dissolved in
2 cups water

Sift together first 4 ingredients. Add whole-wheat flour and oatmeal. Gradually add oil, mixing with a fork, to make a crumbly mixture. Add milk powder dissolved in water, adding more water if necessary to hold together as a lump. Press onto a greased cookie sheet until about an inch thick. Prick with fork and bake at 400°F for 25 minutes. Let cool slightly before cutting. The loaf also freezes nicely; just let it cool completely first.

Note: This moist loaf makes enough for a crowd. Cut it into 50 pieces so each equals: 1 Starch Choice and 1/2 Fat Choice.

Esther Stevens, RDN

August 25, 2003

Appendix F

Participant Thank-you/Invitation

Date: Nov. 3, 2003

Time: 1:00-3:00 p.m.

Haisla Health Centre

[CHR or Diabetes Coordinator]

Diabetes Project Afternoon Tea

In appreciation for your participation, we invite you to hear more about what you said and have fun with some prizes and gift certificates.

Thanks for all your help!

From the Health Centre Staff and
Esther Stevens, Kitimat Hospital
Dietitian

Highlights

- Try a delicious good-for-everyone desert
- Hear a summary of your interview answers
- Clarify your ideas and suggest future program direction

Appendix G

Apple Crisp

1. Mix these ingredients well in a large bowl:

1 cup each large flaked and small flaked rolled oats.
¾ cup each natural bran and whole wheat flour
¼ cup brown sugar
2 Tbsp. "Equal"
¼ tsp. salt
1 Tbsp. cinnamon
½ tsp. nutmeg

2. Add:

1/3 c. warm water with 1/3 c. non-hydrogenated margarine melted in it.

3. Blend well until crumbly. Set aside.

4. Mix these 5 ingredients together:

8-10 apples (about 8 cups), peeled and cut into chunks
2 tsp. lemon juice
¼ cup granulated sugar
¼ tsp. nutmeg
1 tsp. cinnamon

Place in 9" by 13" baking dish. Top with oat mixture and bake at 400^{0}F for about 50 minutes, until apples are just tender. Top with light whipped cream if desired.

Makes 16 servings.

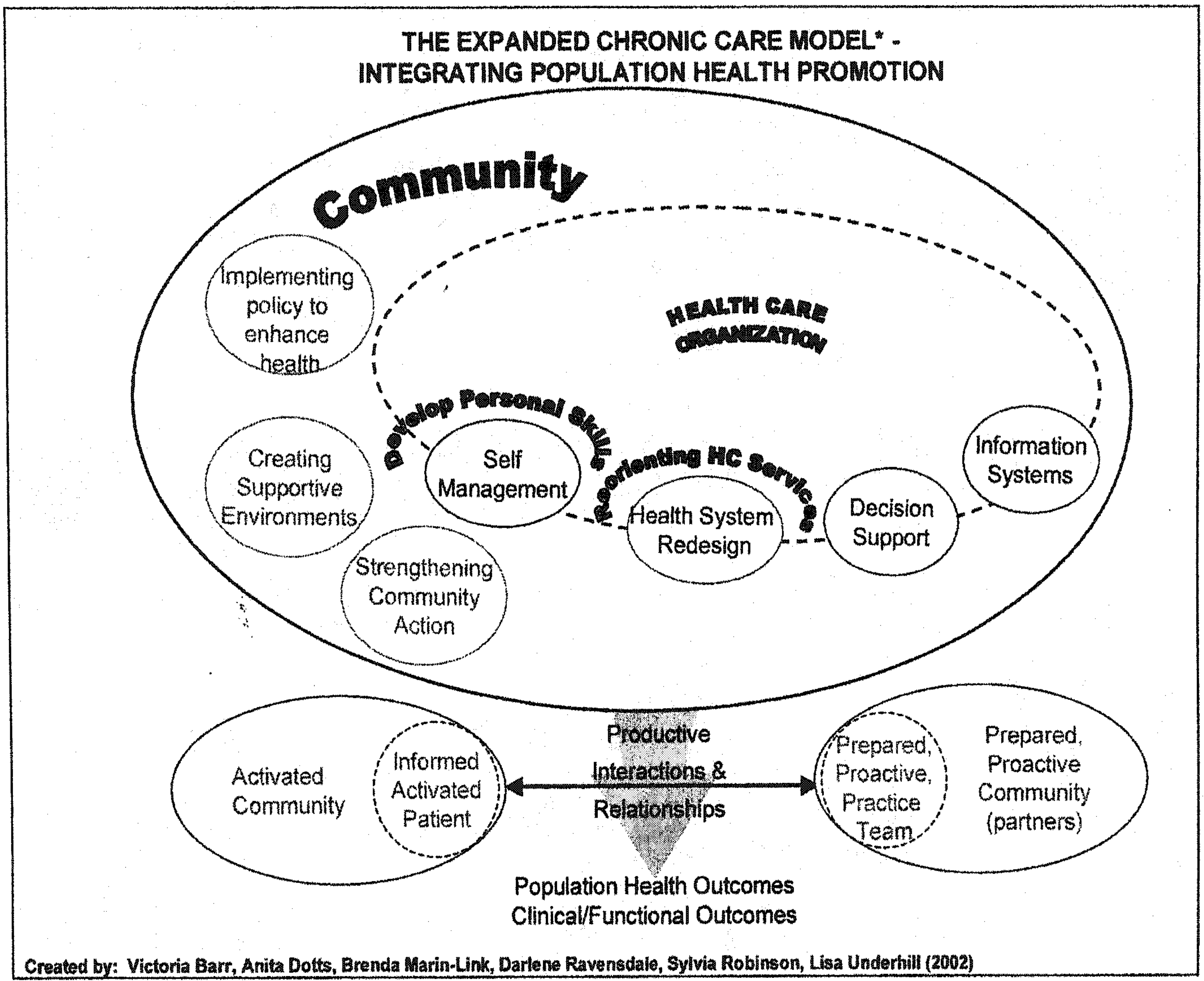
Each serving: 1 Starch, 1 Fruit, 1 Fat, 1 Sugar.

Esther Stevens, RDN

November 2003

Appendix H

Integrating Health Care Services as a Part of the Community
(Barr, et al, 2003; obtained from BC Ministry of Health Services, 2003, December 17).



Used with permission of the authors, April 1, 2004.

Appendix I

NADA Presentation Handout

3rd NATIONAL CONFERENCE ON DIABETES AND ABORIGINAL PEOPLES

Hyatt Regency Vancouver, January 28, 2004 1:30-3:00 pm

Finding Your Place In A First Nations Community

Esther Stevens RDN, Kitimat, and Liza Grant RN, Kitamaat Village, BC.
Northern Health Authority and Haisla Health Centre

Despite efforts at being culturally sensitive, health professionals have few guidelines on how to begin the assessment of diabetes management and prevention needs in an individual community. Successful programs working in one community are not guaranteed similar results in another. This workshop will, first, describe the experience of two health care professionals during a project to assist the Haisla Health Centre staff develop diabetes intervention strategies. Then, a systems approach will be used to analyze how to influence community-specific diabetes outcomes. In examining the real variables involved, the following will be considered: how to determine what help is really desired, whose words to heed and who to contact, which ethical guidelines to follow, obtaining valid community input and analyzing the information collected. Potential hurdles to overcome will be discussed. Finally, each participant will be able to identify workable program development approaches specific to his or her community.

Background to Esther's project:

As part of a thesis for a Master's degree in Leadership and Training from Royal Roads University, "Developing a diabetes program in a First Nations Community", I found no information for health professionals wanting to learn a step-by-step approach. Initially, how does one get to know the culture, be non-intrusive and respectful, establish and prioritize health needs, and learn how to address these needs in a way that maximizes participant input? Many lectures have been presented and teaching tools developed which have either overwhelmed or 'turned off' First Nations. I knew I wanted to gather qualitative data in an ethical, non-invasive, supportive manner.

After establishing individual relationships with key Health Centre staff, we arranged an introductory luncheon, where the project was explained and well received, resulting in my interviewing eleven Haisla. Two participants lived in neighboring Kitimat but were considered residents. They were asked questions regarding their first thoughts when they learned of their diabetes, what information or support would have helped most at that time, if they had ever attended a diabetes education class, what they remembered from it, and what currently concerned them most about their health. They were also asked to recommend any support they would find most beneficial at the time.

Our initial concerns:

Thoughts and concerns during the process:

Our successes and what we each learned:

An Introduction To Systems Thinking And Diagrams

As professional helpers, we may be tempted to fix symptoms rather than the root causes of a problem. Sometimes we confuse the external features of a situation, for example, a chronic disease such as diabetes or obesity, for being the problem elements. These are symptoms that result from *influences* on the elements. Systems, briefly defined, looks at these influences and the way they connect the elements.

> Elizabeth Fadell (2001) challenged the term 'systems thinking' when she said, "…I wish they had never called it systems thinking. It has always struck me as far more like a sensibility, or as sensing connections. Sensing these connections is more than "head" thing, although I really don't believe there actually is such a thing as a perspective just "coming from someone's head", but that's another conversation. Head and heart and gut are connected; after all they are part of a system." Copyright 2001 John J. Shibley retrieved January 24, 2004 from http://www.systemsprimer.com/interview.htm

Shibley emphasizes that in a system, the quality of the relationships between elements is more important then the quality of the elements themselves. The following steps depict the process of creating a systems diagram, with arrows symbolizing the relationships:

1. Sense a story
2. Listen to the story
3. Listen to the story again, with "variable ears"
4. Create variables
5. Create links
6. See if the links make a loop

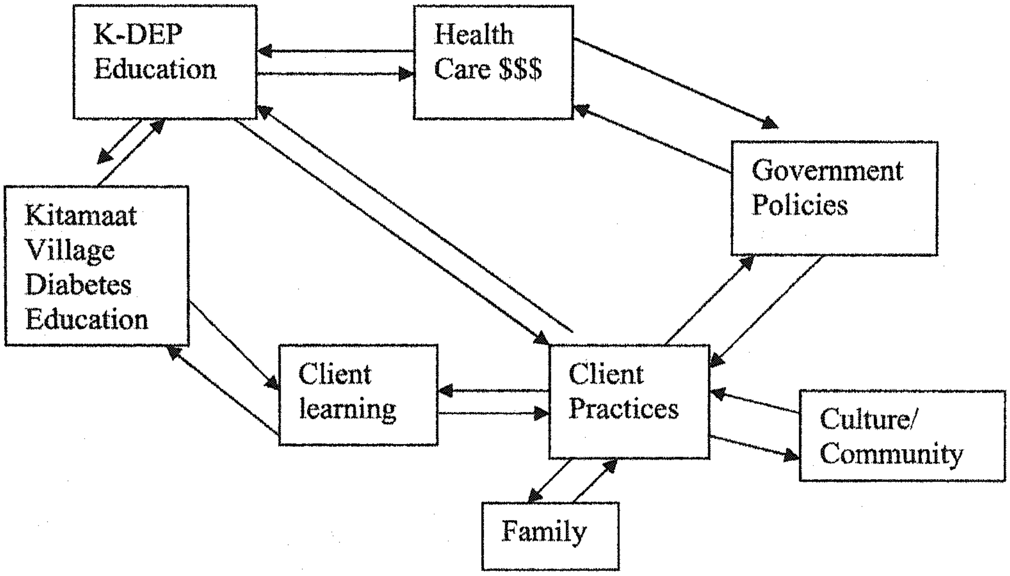
This process helps to make evident assumptions and critical links.

Consider these variables:

- Kitimat Diabetes Education Program – "in town"(K-DEP)
- Kitamaat Village Diabetes Education - "in the Village"(KV-DE)
- Client education
- Client health practices which are also influenced by (and influence) Family, Culture and Government policies

Very briefly, when the diabetes education programs compliment each other, more effective teaching ensues. This improves client health practices, which positively impacts the health of the family and the culture. The utilization of government funding can then be used to support alternate health promotion. Perhaps the formats of the diabetes education programs are the key variables but maybe the influence of family or culture is stronger. And which government is wielding the most influence, band council, provincial, or federal?

The following diagram illustrates these points as a way of opening discussion and checking assumptions.



In drawing the feedback loops, consider these questions:

What does this lead to? (getting the arrow moving forward)

What leads to this? (identifies preceding variable)

Example: Consider the impact of an 'uninformed' health professional on client learning.

Shibley adds two rules:

> Rule #1: As you move through the model, freely use what you learn to revisit and refine work done in earlier stages.
> Rule #2: During it all, attend to the assumptions being made, and the way those assumptions are formed out of data.
>
> One's view of systemic dynamic reflects one's own mental models. As the process above is unfolding, one will stumble over these assumptions. The work of creating variables or links drives people back to clarify their story, and that work in turn forces people to make explicit the assumptions their story is based on, and the data that led them to those assumptions.

Shibley, J. J. (2001). Making loops: A method for drawing causal loop diagrams: creating loops, and so what? *A primer on systems thinking and organizational learning.* The Portland Learning Organization Group. Retrieved January 23, 2004 from http://www.systemsprimer.com/making_loops_intro.htm Copyright 2001 John J. Shibley.

Small group discussion:

(Each group should decide on a timekeeper, flipchart-writer, and a spokesperson) If your group already works together, you may chose to design your own systems diagram. However, in a diverse group, use the above illustration in discussing the following points and, just to help you focus on the links and their variety and strength, I have an assortment of chains for you to use as metaphors for your discussions.

Choose an element and brainstorm what the factors, perceptions, barriers, or challenges that influence the links around it.

Where do you see yourself making the most impact?

Who do you need to contact to discuss your idea(s)?

Conclusion:

Allow time for this to evolve. Relationships take time to grow. Clarify your role to others so they know where they fit in and what they can expect from you. Focus on a manageable bite; you can't eat the whole animal at once.

When working with cultures different from our own, we need to restrain ourselves from culturally modifying pamphlets, posters and presentations until we have invested time in really getting to know the group we are attempting to help. A generic approach such as a First Nations health care manual is only a basic step but is not sufficient. Time must be spent developing a collaborative process of sharing knowledge, skills, values and culture with the specific target group, to be a learner, not a teacher, open to their ways and not constrained by one's own pre-existing knowledge.

(Liza to close with talking about the importance of collaboration and clarifying assumptions.)

Closing:

In closing, I looked for a significant quote but decided to leave you with an experience that I find meaningful. This is my Tibetan 'singing bowl'. The resonance that this little bowl gives off reminds me that I am just a pebble but the ripples of who I am extend further than I can imagine. I am at the centre of my system; you are at the centre of your system. Take good care of you so that when our ripples meet, they joyously splash.

KITAMAAT HEALTH CENTRE
KITAMAAT VILLAGE COUNCIL
Haisla PO Box 1041
Kitamaat Village, BC
VOT 2B0

This letter confirms the authorization of Esther Stevens (learner's name) to use the following Haisla Health Center – related materials:

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2) Photo of Haisla Health Center vacant boardroom, showing categorization of transcripts mounted on the walls, allowing participants to read what they had said as part of his/her Major Project/Thesis for the partial requirements of a Master of Arts in Leadership and Training at **Royal Roads University**.

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Mary Nyce,
Director of Health
Kitamaat Village Council
April 2nd, 2004

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- Northern Health Authority. (2003c). *Map of region and service delivery areas.* Retrieved February 12, 2004, from http://northernhealth.ca/nhs/contacts_home.asp?articleid=13&zoneid=26
- Conceptual Organization Chart of the Northwest Health Services Delivery Area,

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> Barr, V. J., Robinson, S., Marin-Link, B., Underhill, L., Dotts, A., Ravensdale, D., Salivaras, S. (2003). The expanded chronic care model: An integration of concepts and strategies from population health promotion and the chronic care model. *Hospital Quarterly*, 7(1), 73-82.

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