Living with a Diagnosis of Cancer in Canada's Western Arctic

A project examining the experiences of cancer patients at
Stanton Regional Health Board Medical Clinics

By

Ruth A. Robertson RN

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We accept this thesis as conforming to the required standard

Project Sponsor, Dr. Pierre Lessard

Faculty Supervisor, Fred Jacques, MA

Committee Chair, Douglas Hamilton, PhD

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ABSTRACT

Two years ago one of the staff members at the Stanton Regional Health Board (SRHB) Medical Clinics was diagnosed with cancer. Although SRHB Medical Clinics health care providers are part of the healthcare system and understand the processes, this experience brought a new appreciation for what it was actually like for a cancer patient to try and navigate *through* the system. It became evident that as health care providers, our understanding of the patients' perspectives of their needs -- in relation to the services provided -- was limited.

An action research study was undertaken to answer the broad question: From the patients' perspective, what factors contribute to the effectiveness of services offered by Stanton Regional Health Board Medical Clinics, to patients living with a diagnosis of cancer in Canada's Western Arctic? This research presents the stories of thirty four cancer patients who received services through Stanton Regional Health Board Medical Clinics. The data was gathered through in–depth interviews. Transcribed interviews were then coded and analyzed interpretively to identify categories and themes that offered insights about the experiences of cancer patients. A focus group of health care providers was then asked to respond to the questions from the patients' perspective. This gave care providers a voice in the process while providing effective triangulation of the primary data obtained from the participating patients. A compilation of all data collected was used to answer the research question.

Cancer patients in the Western Arctic who participated in this study believed that there were two main aspects which contributed to effective care at Stanton Regional Health Board Medical Clinics: a well organized, systematic approach to services, and services that are offered within a supportive and caring environment. Regarding a well organized systematic approach, patients spoke of the significance of being able to readily access services in the Western Arctic. They spoke of the importance of the continuity of care within this service. Evident throughout the patients' stories was the value of co-ordination of services within SRHB Medical Clinics and other SRHB units, between SRHB and their family physicians and health centers in their home communities as well as between SRHB health care providers and health care providers in "the south." The second over arching theme was one of health care services, which are provided, in a supportive and caring environment. This was reflected in the patients' stories of the information they received and of knowing what to expect. It was about having competent and caring care providers. Their stories reflected a wish to have their personal values, beliefs and traditions recognized and accepted.

This study was intended as an exploratory and descriptive study and as such has provided insights and direction for SRHB to begin the transition towards a co-ordinated Cancer Care Program at Stanton Regional Health Board.

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CHAPTER 1 – STUDY BACKGROUND

The Opportunity

"We are afraid of cancer. In fact we usually feel more frightened of cancer than any other equally serious (or equally curable) medical condition" (Buckman, 1995, p. 15). Cancer continues to be the leading cause of premature death in Canada and is predicted to be the number one health problem of the next century (Health Canada, 2001a). Between 1991 and 1996, the leading cause of all deaths in the Northwest Territories (NWT) was cancer (25%). The major cancers leading to death for both men and women in the NWT were lung and digestive cancers. These accounted for more than half the cancer-related deaths. This is comparable to the national cancer mortality rate. In 1999, 97 new cases of cancer were registered with the NWT Cancer Registry compared to 98 new cases in 1998 (Government of the NWT, 1999).

While a diagnosis of cancer invokes fear, and the statistics are alarming, there is cause for hope in knowing that the greatest numbers of cancers are understood, treatable, and preventable. One in three individuals diagnosed with cancer in the twenty-first century is expected to survive (National Cancer Institute of Canada, 2000). There is a real need to deal with the prevalence and rising incidence of cancer. This need is driven, not only by economic costs that will be imposed on our healthcare system, but also by the significant impact on human suffering in individuals, families, and communities (Health Canada, 2001b).

As Canadians we are privileged to receive healthcare services through a publicly funded system. The Canada Health Act of 1984 guarantees that healthcare for Canadians will be comprehensive, universal, accessible, portable, and publicly administered (Health Canada, 1999b). The Western Arctic is a vast geographical region covering approximately one-quarter of Canada's landmass. Small isolated communities, diverse cultures, scarce resources, and an overwhelming number of significant social and health issues limit the ability of many of the communities to readily meet healthcare needs of cancer patients. The majority of the residents in the Western Arctic live in remote communities with limited medical treatment facilities. Approximately 50% of the population of the Western Arctic is of aboriginal descent (GNWT, 1999).

Cancer patients in the Western Arctic have unique and diverse needs when gaining access to the healthcare system. The most frequently reported need of cancer patients is for information regarding their disease, their treatment, and how events will unfold (Buckman, 1995; Degner, Davidson, Sloan, & Mueller, 1998; Howell & Jackson, 1998). Further evidence suggests that patient satisfaction with services is not only related to hospital care, but equally -- or more so -- to the care received through ambulatory, outpatient, and community care services (Klastersky & Razari, 1994). The literature refers to supportive cancer care as those health services-related activities that are designed to help cancer patients and their families with their experience. It includes services designed to meet the physical, informational, psychological, social, and practical needs of patients (McMaster University, 2000).

There are no formal cancer treatment centres in the NWT. The Stanton Regional Health Board (SRHB) Medical Clinics located in Yellowknife provides a comprehensive range of primary and secondary health services and a number of specialised tertiary services on an inpatient, outpatient, and outreach travel basis. Services provided to patients with diagnoses of cancer are a combination of each specialty service rather than a formalised cancer care program. Buckman (1995, p. 10) states that:

> Although one in three Canadians will develop cancer in his or her lifetime and all of us will have close friends or family members who develop cancer, a diagnosis of cancer is always a shock and almost always completely changes one's whole approach to life and living.

Two years ago one of our staff members at the SRHB Medical Clinics was diagnosed with cancer. This brought the healthcare system in which we work closer to home for each of us. It offered a glimpse of the services we currently provide as seen through the eyes of a patient who is very familiar with the system. Although we are part of the healthcare system and understand the processes, it brought a new appreciation for what it was actually like for a cancer patient to try and navigate *through* the system. It became evident that our understanding of the patients' perspectives of their needs -- in relation to the services we provide -- is limited.

Having a colleague I have worked closely with for many years diagnosed with cancer has served to heighten my awareness of the need to better understand the experiences of cancer patients who receive services through the SRHB clinics. Based on my observations and anecdotal comments from patients, there seem to be many positive aspects to the services provided, as well as opportunities for improvements.

The Focus

The focus of this study is the experiences of patients living with a diagnosis of cancer in Canada's Western Arctic. The purpose of this study is to describe, from the patients' perspectives, their experiences with navigating through the healthcare system to access necessary medical treatment. The information will be used to inform the SRHB Medical Clinics staff and administration about cancer patients' experiences and their needs. I believe that this information can be the first step towards improving the services that the SRHB Medical clinics provide to cancer patients. This understanding will serve to enhance collaboration among individuals, groups, and agencies that have roles to play in the cancer patient's journey through the healthcare system.

The Research Question

The research question and sub-questions that the study addresses are:

> From the patients' perspective, what factors contribute to the effectiveness of services offered by Stanton Regional Health Board Medical Clinics to patients living with a diagnosis of cancer in Canada's Western Arctic?

Sub-Questions

1. What were the experiences of patients living in remote parts of the country when they found out they had cancer?
2. What was the cancer patient's experience navigating the healthcare system? What challenges did she/he face? What information helped? How could information be improved for future patients?
3. What or who supported patients through the process of being diagnosed and treated for cancer? How did they cope? Who and/or what helped them to survive?
4. Based on their own personal values, traditions, and beliefs, what was important to patients in relation to the services and care they received?
5. How could this experience have been better for the patients? What could have been done at the clinic to make it a better experience?

Definitions

For consistency and clarity, definitions of selected terms used in this paper are specified below.

Aboriginal - Refers to all persons indigenous to Canada of North American Indian, Inuit, or Metis ancestry including those in the Indian Register (Federal, Provincial, and Territorial Advisory Committee on Population Health, 1999, p. 7).

Canada Health Act (1984) - The five principles of the Canada Health Act are:

1. **Comprehensiveness** - all medically necessary healthcare services provided by physicians or in hospitals must be covered by provincial healthcare plans.

2. **Universality** - all residents of a province are entitled to insured services through uniform terms and conditions.
3. **Portability** - host-province rates apply to healthcare services provided elsewhere in Canada and there are national standards for out-of-country benefits. The province-of-origin's consent for the coverage of elective services provided to a resident outside of the province is required.
4. **Accessibility** - provincial healthcare plans must provide for insured health services through uniform terms and conditions and must not impede or prevent reasonable access to these services by any means. and
5. **Public administration** - the Canada Health Act describes the elements of public administration as (1) administration of the insurance plan without profit. (2) run by a public authority appointed or designated by the provincial government and responsible to government. and (3) regular audits of the public authority.

Care Provider - Any individual who provides a service to a patient. This includes. but is not limited to physicians. nurses. physiotherapists. speech and language pathologists. audiologists. medical travel agents. interpreter services. home care. medical social workers. laboratory or radiology technologists. and ophthalmic technologists.

Chemotherapy - The use of chemicals to treat cancer cells.

Client - Patient.

Dene - The Dene are the aboriginal people of an area in Canada, which stretches from Hudson Bay through the NWT and Yukon Territory to the interior of Alaska and from central Alberta to the Arctic Ocean. This includes the northern most parts of Manitoba, Saskatchewan and British Columbia. The word "Dene", when translated, encompasses an understanding that Dene people flow from Mother Earth and are a people of the Creator and Creation. While there are many distinct regional groups, each with their own territory and dialect, all Dene share a common ancestry and come from the same language family. In the Northwest Territories, there are 5 such groups. Their regions and languages are as follows: Mackenzie Delta Region (Gwich'in); Sahtu Region (North Slavey); Dehcho Region (South Slavey); South Slave Region (Chipewyan); North Slave Region (Dogrib).

Gynaecology - Services associated with functions, diseases, and hygiene of the genital tracts of women.

Incidence rate - Frequency of occurrence.

Internal medicine - Services associated with the branch of medical science which specialises in the diagnosis and medical treatment of patients as opposed to surgical and obstetrical treatment.

Inuit - The Inuit of Canada live mainly in the coastal areas above the tree line in the NWT and Nunavut. There are 40,000 Inuit around the world and close to 16,000 are in the NWT and Nunavut residing in more than 30 communities. The Inuit population includes several regional groups sharing a common heritage and one language in several distinct dialects.

Metis - The Metis of the Western Arctic and sub arctic regions of the NWT number approximately 7,000 people. They are the offspring of three merging cultures – Red River Metis, Euro-Canadian, Dene (Slavey, Gwich'in, Dogrib, Chipewyan) and Cree families.

Mortality rate - Frequency of death.

Northwest Territories - Unless otherwise noted, refers to the NWT after April 1, 1999, following the division of the NWT and creation of the territory of Nunavut.

Nunavut – Canada's newest territory formed on April 1, 1999. Locate in Canada's Eastern Arctic.

NWT Health Status Report, 1999 - Statistics in this report have been adjusted to reflect the NWT population. These statistics do not include residents in Nunavut who, prior to April 1, 1999, were included as residents of the NWT.

Obstetrics - Services associated with prenatal, labour and delivery, and post-natal care of women.

Oncology - Services associated with the branch of medical science dealing with the study of tumours.

Ophthalmology - Services associated with the branch of medical science dealing with the eye.

Orthopaedics - Services associated with the branch of medical science dealing with diseases, deformities and trauma of bones, joints, and spine.

Otorhinolaryngology - Services associated with the branch of medical science dealing with ears, noses, and throats.

Patient - Refers to an individual or individuals who have been diagnosed with cancer and are living in the NWT. May be referred to as client.

Stanton Regional Health Board Medical Clinics - Refers to the provision of consultative physician specialist services in otorhinolarynglogy: obstetrics and gynaecology; gynaecological oncology; internal medicine: orthopaedics; ophthalmology; paediatrics: and general surgery.

Urban - Belonging to or included in a town or city. an urban population (Oxford Dictionary. 1991. p. 1.351)

Western Arctic - Refers to the NWT and the Kitikmeot region of Nunavut.

The Organization

Stanton Regional Hospital (SRH) is one-hundred-bed. fully accredited regional referral centre located in Yellowknife. It is the largest referral centre in the NWT with approximately 450 employees and an annual operating budget of $55 million (SRHB. 2000a). SRH provides services to Canada's Western Arctic. including the Kitikmeot region located in the newly formed territory of Nunavut. The NWT and the Kitikmeot region have a combined estimated population of 46.464 people scattered over 1.9 million square kilometres. The population is composed of four main cultural groups: Dene. Metis. Inuit. and non-aboriginal residing in 37 communities with populations ranging from 50 to 18.000 residents (GNWT. 2000a).

Access to communities north of Yellowknife is primarily by air. Regularly scheduled visits by physician specialists, general practitioners, and other healthcare professionals supplement the ongoing care provided in the communities. Most outlying communities have health centres staffed by registered nurses. Patients requiring care not available in their home communities are flown to the nearest regional referral centre. (Fort Smith, Hay River, Fort Simpson, Inuvik, Yellowknife).

All Western Arctic residents registered with the NWT Health Care Plan (HCP) or the Government of Nunavut (GNU) Health Care Plan receive standard coverage for hospital and physician services. Cancer is classified as a Specified Disease condition and may qualify the patient for extended health benefits. Certain additional health benefits are provided to registered First Nations or Inuit under the Federal government Non-Insured Health Benefits (NIHB) plan. If the cancer patient in either group qualifies for additional coverage under an employer health insurance, she/he must first submit expenses to that plan.

Both the GNWT and the GNU have Medical Travel Policies designed to provide assistance to residents who are required to travel for medical reasons and who are not eligible to receive assistance through employer benefit plans or other means. Benefits generally include transportation costs to and from the nearest approved treatment centre. The responsibility for administering medical travel benefits for eligible residents rests with the Health Board in each region.

A diagnosis of cancer for a patient in the Western Arctic may require frequent trips from the patient's home community to Yellowknife or southern facilities to receive healthcare services. Travel can increase costs and stress to the patient. Often, patients are unsure of their employer benefit plans. Cancer patients who do not require hospitalisation usually have the option to stay at a hotel, hospital, hostel, or medical boarding home with partial or full coverage of the costs through the Extended Health Benefits Plan. Stanton Regional Health Board (SRHB) is responsible for medical travel benefits not covered by employer benefit plans for residents of Yellowknife, Fort Simpson, Hay River and a few surrounding communities. The number of medical travel warrants issued through the SRHB Medical Travel department to NWT residents requiring services out-of-Territory for a diagnosis of cancer has continued to rise significantly over the past three years from 303 warrants issued in 1996 to 507 issued in 1999 (SRHB, 2000b).

Approximately 55% of the patients receiving services at Stanton Regional Hospital are aboriginal. In accordance with the NWT Official Languages Act, services at SRHB are provided in nine aboriginal languages and their dialects, which vary between communities (Bouvrette, 1995). In earlier times, cancer was not a disease known to aboriginal people. This was probably due to the fact that its processes are primarily internal and not outwardly evident, and because people did not generally live long enough for the disease to manifest itself. Consequently, cancer is sometimes called a "white man's disease" and is seen as yet another scourge such as tuberculosis, brought North by white explorers.

"Cancers vary enormously in their potential for causing harm or threatening life. The majority of cancers afflicting people in the NWT are linked to lifestyle choices and, to a large extent, are preventable" (Corriveau, 1997, p. 5). The Northwest Territories population is relatively young with the life expectancy of all population groups steadily increasing over the past two decades. Cancers tend to appear later in life. As the population continues to age, the incidence of cancer can also be expected to increase. "Population projections suggest that, by the year 2008, the number of elders in the Northwest Territories will more than double, while the number of people less than 20 years old will only increase by 15%." (GNWT, 1999, p.2).

Smoking is considered a leading risk factor in lung cancer. Lung, oral cavity, esophagus, stomach, and breast cancers have established links to tobacco smoke. The NWT has a rate of smoking much higher than that of the rest of Canada. More than 45% of Northwest Territories residents, 12 years of age and older, reported being current smokers compared to less than 30% nationally. A higher percentage of aboriginal people over the age of 15 reported being smokers than non-aboriginal people over the age of 15 years. (NWT Labour Force Survey1999 as cited in the GNWT Health Status Report, 1999, p. 32.)

Lung cancer is also the most frequently diagnosed form of cancer in the NWT, appearing in 30% of diagnosed males and 22% of diagnosed females. Nationally, lung cancer remains the leading cause of death for both genders with almost one-third of the cancer deaths in men and almost one-quarter in women due to lung cancer alone (National Cancer Institute, 2000).

The incidence of lung cancer in the NWT, especially in women, is predicted to increase as more females are smoking than males. It is well known that the use of tobacco is a preventable factor associated with a wide range of diseases, including cancer. Based on the prevalence of smoking, tobacco was estimated to be the cause of nearly one-quarter of all deaths from cancer, circulatory, and respiratory diseases (GNWT Health Status Report, 1999, p. 32).

Prior to 1988, the NWT healthcare system relied primarily on specialist services provided by consultants in Edmonton, Alberta, which is 90 minutes away by air and 1,400 km. by road. Historical referral patterns had developed where most residents requiring medical services provided by a specialist were flown to Edmonton.

At the time, bringing specialists to the north offered short-term solutions to locally unmet healthcare service needs. The system however, created a dependence on out-of-Territory healthcare service providers, rather than fostering the development of services in the NWT. This is what Senge (1990, p. 381) refers to as "shifting the burden to the intervenors" whereby systems develop a dependence on external contractors instead of training and developing their own people and systems to lead to long-term solutions.

In 1992, the GNWT and SRHB took a broader "systems thinking" approach to the delivery of healthcare. Strategies were developed which shifted the focus from planning for individual components of the system to considering the system as a whole.

The focus has shifted to, whenever possible, enhancing the capabilities of providing resident consulting specialist services in the NWT -- no longer reacting to the present but rather planning for the future.

Since 1992, SRHB has repatriated a number of the specialized services, which were traditionally provided in Alberta. The SRHB Medical Clinics provide consultative physician specialist services in otorhinolarynglogy, obstetrics and gynaecology, gynaecological oncology, internal medicine, orthopaedics, ophthalmology, paediatrics, and general surgery. Services provided to patients with a diagnosis of cancer include components from each specialty, rather than a formalized cancer program. The physician specialists and SRHB Medical Clinic staff work closely with other members of the hospital healthcare team including general practitioners, medical social workers, rehabilitation staff members, respiratory therapists, dieticians, pharmacists, medical day care unit staff, chemotherapy program staff, palliative care team members, home care team members, and language and cultural services providers. The addition of mammography screening services and CT scanning capabilities has enhanced the capability for early detection and diagnosis of certain cancers. The ongoing expansion and development of these services allows SRHB to continue to repatriate acute care services from Edmonton.

Patients with a diagnosis of cancer may gain access to the NWT healthcare system from several entry points. A general practitioner in Yellowknife, a general practitioner from one of the outlying communities or a nurse in a remote health centre may refer the patient to the appropriate specialist at SRHB.

As well, a patient may be sent directly to an urban centre for care. The patient may also be seen by the SRHB specialist at some point in the course of diagnosis and treatment -- or in fact, may never be seen at all by an SRHB specialist.

Depending on the type and severity of the cancer involved all or part of the treatment may take place outside of the NWT. Generally, patients from the NWT receive initial non-surgical cancer treatment from the Cross Cancer Institute (CCI) in Edmonton, Alberta. The CCI is one of two tertiary cancer treatment centres in the province of Alberta under the direction of the Alberta Cancer Board. In cases where ongoing treatments are required (such as chemotherapy), the patient may return with a medication and treatment protocol to be administered by healthcare providers at SRHB.

In the fiscal year 1999-2000, the SRHB Medical Daycare Unit administered 174 chemotherapy treatments and performed 144 chemotherapy assessments. In the first five months of the 2000-2001 fiscal year, 149 chemotherapy treatments were already completed, along with 95 chemotherapy assessments. This is due to an increase in the number of patients receiving treatment as well as an enhanced level of chemotherapy services provided by SRHB (SRHB Facts & Figures Binder, 2000b).

One service, which is provided through the SRHB Medical Clinics, has demonstrated positive outcomes for certain types of cancer patients. Regularly scheduled visits by a gynaecological oncologist as part of the Obstetrics and Gynaecology (Ob/Gyn) Program allows cancer patients to be seen and most often treated at the SRHB Medical Clinics.

This arrangement has been in place for twenty-two years. The service model utilized for all gynaecological oncology parallels a quality management process - a systematic and cyclical approach to cancer care. For example, there are standards in place in the Western Arctic for screening for cervical cancer. These standards are incorporated into the routine patient examinations completed by family physicians and nurses in health centres. Abnormal test results are flagged and the patients are referred to the Ob/Gyn Program at SRHB Medical Clinics for further assessment and treatment. If necessary, patients are then referred by the resident Ob/Gyn to the gynaecological oncologist on the next scheduled visit to SRHB Medical Clinics. Once the patient is receiving gynaecological oncology services through the SRHB program, the oncologist monitors the patient for the duration of the cancer treatment and any necessary follow-up. To maintain continuity of care, when a gynaecology oncology patient is required to travel to Edmonton for treatment not available at SRHB, the same gynaecological oncologist who provides services through the SRHB Medical Clinics provides care for the patient. As well, all pathology results are systematically tracked through the Ob/Gyn Program and the Cross Cancer Institute in Edmonton and the University of Alberta Hospital maintains a database. Family physicians and the nurses in the patient's home community are kept informed and involved in routine care and follow up of the patient. A patient recall list is in place at SRHB Medical Clinics and patients are tracked accordingly. In general, most patients require minimal care in the south as a result of a comprehensive Northern Program.

Feedback from continuous patient surveys and interviews indicate that patients believe they receive consistent, comprehensive, and timely services.

In 1997, discussions were held between representatives of the CCI and SRHB as a first step towards the development of a formal relationship. The goal was to provide a mechanism to keep SRHB abreast of developments at CCI, to strengthen communication, and to provide learning opportunities for nurses, physicians, and pharmacists involved in providing care to chemotherapy patients. The focus of the initial discussions was primarily the chemotherapy program. In the fall of 2000, a follow-up meeting was held with representatives of the Alberta Cancer Board. SRHB representation was expanded to include all key stakeholders providing care to cancer patients at SRHB. Future plans for a more comprehensive approach to cancer care services at SRHB include electronic access to CCI clinical treatment protocols and fully integrated patient charts, telehealth patient consultations, telehealth educational sessions, and onsite oncology visits for educational purposes. A review of the chemotherapy program at SRHB is scheduled for midyear 2001 with continued support from the CCI for nursing and pharmacy oncology certifications.

There are a limited number of community-based organisations in the Western Arctic, which provide support to cancer patients. Most of these groups or organisations are located in Yellowknife. The Alberta/NWT division of the Canadian Cancer Society (CCS) serves the NWT from its office located in Yellowknife. The office is open part-time and employs a part-time executive director.

The agency's main activities are to respond to requests for information, education, and support for all types of cancer. In response to the unique composition of the population in the Western Arctic, the Canadian Cancer Society, in partnership with SRHB, operates a toll-free cancer information line in all of the Western Arctic aboriginal languages. Callers speak with trained medical interpreters who use the CCS national database to answer questions. The agency provides educational materials and may assist with funding of educational projects. The primary program currently available through the CCS Yellowknife office is CanSurmount, a support group for cancer patients and their families. Volunteers with the program have either experienced cancer themselves or have had a family member with cancer. Currently, the agency has a limited number of volunteers. The executive director has expressed an interest in increasing the overall volunteer base.

The NWT Breast Health/Breast Cancer Action group is another formal volunteer committee made up primarily of women who are breast cancer survivors or have a family history of breast cancer. The public, government, and non-government agencies in Yellowknife, are increasingly recognizing this group for its proactive work on breast cancer issues in the Western Arctic. The main goal of the group is to increase and/or to improve breast health and breast cancer information, services, and support available to NWT women.

In May 1996, a summary discussion paper, The Information Needs of Women Regarding Breast, Cervical and Lung Cancer, identified the many continuing problems with meeting the needs of both healthcare providers and cancer patients.

Summary comments regarding the NWT Healthcare system that emerged include the following:

- *There needs to be much better information-sharing by health professionals in the system in order to meet the survivors' needs. To address this issue, much closer interagency co-operation, liaison, and protocols will need to be developed,*
- *Southern and Yellowknife regional health care providers need to know what support resources there are in the survivor's home community, and*
- *Health professionals in the NWT need to know what resources are available in southern Canada to support the survivor while at the southern hospital, clinic, or medical boarding home.*

In an NWT Breast Health/Breast Cancer Action Group planning session held in February 2000, it was noted that while SRHB is seen to provide good care to cancer patients, there is still not an overall co-ordinated approach. Although the work done by the group addresses the needs of women with cancer in the NWT, the information gained can be applied to all cancer patients. The work of the group provides further support for the need to fully investigate the needs of all cancer patients living in the NWT. The hope is that the information received from cancer patients will provide a foundation for the development of a formalized cancer care program for cancer patients living in the NWT and Nunavut.

Potential Reasons for the Opportunity

The Stanton Regional Health Board offers a broad range of programs and services to support the health and well being of the people it serves. Varying levels of service and support are available to patients with a diagnosis of cancer. Many services are very effective. Some could be improved. To quote a frustrated patient of the SRHB Clinic:

> We need to look at what services we provide to cancer patients and how we provide them. I have worked in the system for 20 years and at times I found it frustrating and uncoordinated. Imagine someone who does not speak English and comes from a smaller community and does not understand the healthcare system.

These sentiments were echoed in community presentations to the GNWT Minister's Forum on Health and Social Services. In 1999, the GNWT held extensive community consultations to determine the priorities of the residents of the NWT. The forum heard that the residents wished to see better co-ordination and integration of health programs and services.

During the consultations, people expressed concerns about overall gaps in healthcare services. For example, services were not available when people needed them or they were not offered at all. In addition, services for people with special or complex needs were thought to be lacking or poorly co-ordinated. People also said they wanted to see more services provided closer to their families and communities. People recognized the need to travel for some services such as specialised medical treatment.

Certain services, such as long-term care, palliative care, and birthing services, were felt to be priorities, and needed to be provided closer to home (GNWT Final Report of the Minister's Forum on Health & Social Services, 2000c).

According to the presenters to the Forum, a providing and receiving quality service was a high priority for the public and the caregivers. Quality of care depends on worker skills and training and availability of information, equipment, supports, and funding. This means some services cannot be provided as close to home as people would like. With the small, remote population of the NWT, there are simply too few people for some specialised services to be provided in each region, or even in the NWT. Balancing quality of care with providing services closer to home remains a challenge.

Currently there is no mechanism or process, which integrates services between SRHB Medical Clinic, other care providers, community agencies, and services provided in the south. This poses significant barriers to the planning, co-ordination and provision of services. In recent years, scarce resources and budget deficits have posed challenges to Stanton Regional Health Board. Administration is faced with difficult decisions regarding the allocation of resources. Given the current environment, SRHB administration will need sound information to make intelligent and informed decisions regarding future directions for the services provided to patients living with cancer in the Western Arctic. An essential first step in planning a course of future action for services is to listen to the cancer patients about their experiences and what is important to them.

The knowledge gained from the patients' first hand experiences can be used to inform staff, administration, and community partners about the issues and challenges faced by cancer patients. In turn, this inquiry will foster positive working relationships within the organisation, with other agencies, and within the community. In the absence of change, the cycle of questionably effective service delivery will continue.

CHAPTER 2 – LITERATURE REVIEW

Review of Organizational Documents

Stanton Regional Health Board is committed to providing care that meets or exceeds high quality standards and as a regional referral center strives to offer services closer to the patients' home and in a more familiar cultural environment. The Board of Trustees of Stanton Regional Health Board provides leadership to the organization using a policy governance model that emphasizes values, vision, empowerment of the board and staff and focuses on achieving results. This approach assists the Trustees in establishing strategic directions for the organization, to set out how they will work together as a board, and to clearly outline the constraints the Chief Executive Officer and staff will work within. SRHB is a results oriented Board with results policies which are developed based on the human needs that are to be met by the organization (Stanton Regional Health Board, 2001b).

Mission Statement

The Health Board's stated mission is "Restoring health with dignity," with expected outcomes expressed as results policies. The 2001- 2004 draft business plan presents several value statements and goals that were created to achieve results.

Value Statements

1. Comprehensive Care - SRHB follows a holistic approach to individual health care, one that recognizes the interaction of biological, sociological, spiritual, economic, and environmental factors.

2. Right to Health Care - All SRHB patients have the right to determine their own health care based on their individual needs, regardless of religion, cultural practices, or customs.

3. Partnerships - SRHB patients' health care needs can be most effectively met through a team approach that includes input from the organization, the community, and other agencies.

4. Education - The quality services provided by SRHB are made better through ongoing education and research.

5. Respect for the Individual - Respect for the dignity and the worth of individuals is essential. Each individual is respected and appreciated for their uniqueness. Each individual is has the right to receive care with dignity and has the right to die with dignity and peace.

(SRHB, 2001b, p.2)

Goals

According to the SRHB 2001-2004 Business Plan the five stated goals which will assist the organization to achieve desired results are:

1. To provide clinical and support programs consistent with the role of a community and regional referral centre;

2. To provide health care that meets or exceeds recognized quality standards:

3. To provide and maintain sufficient and appropriate staffing for approved programs:

4. To provide a physical facility which assists the effective delivery of care: and

5. To maintain financial solvency within available resources.

(SRHB. 2001b. p.8)

In this study. I will analyze the stated value of ongoing education and research as an essential step in planning for more comprehensive. holistic health care services. Specifically. I will look at service development decisions that are made based on information provided by cancer patients. Since many of these patients are Aboriginal. the study will also focus on the secondary issue of providing culturally appropriate care.

In addition, patient participation in this research will mirror the growing trend of patients becoming partners in determining their health care plans and approaches. In turn this will validate that their issues and concerns are being given serious consideration in care planning.

Review of the Supporting Literature

To prepare for this project a review of the literature was undertaken to gain perspective on the following concepts:

1. Health care in remote and rural areas.
2. Culture and health care.
3. Client-centred care.
4. Supportive care.

Health Care in Rural and Remote Areas

A review of the literature reveals a strong interest in remote and rural health care, and a recognized need to consider rural perspectives when planning for and providing health care services. However, researchers consistently fail to come up with universally accepted definitions of "rural" and "remote." "Rural" is often used interchangeably with the words "northern," "remote," "isolated," "under-serviced," and "culturally diverse," even though, as Watanabe & Casebeer (2000) points out, they carry very different connotations:

> There are special characteristics of remote, isolated, northern, and cultural communities that deserve recognition, since these words are not synonymous with "rural." These words cannot be sufficiently defined to reflect the unique and dynamic nature of the various regions and communities that could be labeled as such. (p. 15)

Geographically, Canada's Western Arctic is the country's northernmost region, lying north of the 60th parallel. McNiven (1999) linked the concepts of "north" and "rural" when he wrote:

> There is no doubt that Canada has a north, but where is it? . . . Given the interaction and the symbiotic relationship between climate, human activity and the earth we inhabit, it is clear that no single variable is sufficient to define what is considered to be 'the north.' (p. 4)

Defining rural and remote populations is more complex than simply measuring population density or distance to urban centers. Ehrensaft and Beeman (2000), Pong (2000), Watanabe and Casebeer (2000), and others argue that geography, climate, economics, and social and cultural dimensions must all be considered. For purposes of this thesis, it is important to make distinctions between "rural areas" and "rural towns." Canadian communities of 10,000 people or less are usually classified as "rural" (Leduc, 1997; Mendelson & Bolman, 1998; Rourke, 1997). Statistics Canada officially defines "rural and small towns" as a) communities outside of Census Metropolitan Areas (CMAs) that have populations of less than 100,000; or, b) Census Agglomerations (CAs) with populations between 10,000 and 99,999, and where less than 50% of the work force commutes to a larger urban center.

"Rural areas" are those that do not come under the CMA or CA definitions. Accordingly, provincial rural populations between 1991 and 1996 ranged from 15% in British Columbia and Ontario to 46% in the Atlantic Regions and to 59% in the Territories [Yukon, NWT, Nunavut] (Health Canada, 1999c). Finally, the Canadian Association of Emergency Physicians' Rural Committee defines "rural remote" as "rural communities about 80-400 kilometers or about four hours transport in good weather from a major regional hospital" (p. 12).

Much of the current health care literature makes distinctions between rural and urban areas based on physician availability (Canadian Medical Association, 2000; Leduc, 1997; Ng, Wilkins, Pole & Adams, 1999; Rourke, 1997). Leduc (1997) has proposed a six-variable model for quantifying rural physician practices which includes a) distance from the closest advanced referral center, b) distance from the closest basic referral center, c) catchment area population, d) number of general practitioners, e) number of specialists, and f) the presence of an acute care hospital.

Ng et al. (1999) used 1993 data from Statistics Canada to examine the aerial proximity [distance by air travel] of the Canadian population to access physician services. They reported that even though there were only half as many physicians per 1,000 residents in rural and small Canadian towns, two-thirds of those residents lived within 5 km of a physician and only 7% lived beyond 25 km of a physician. In remote communities, most of them in the northernmost reaches of the country, over two-thirds of the population live more than 100 km from a physician.

The research team also presented evidence suggesting that the cost of receiving health care in remote areas is not a barrier to access, even when transportation to rural towns or urban areas is added. In addition, Leduc (1997) commented on the benefits of skilled health care professionals who are not physicians that serve rural populations. Although residents in Canada's Western Arctic region are widely dispersed, the majority of their communities have health centres staffed by registered nurses, intermittent physician services in smaller communities, and regular physician services in some of the larger ones.

Why is a Rural Perspective Important?

The Organization for Economic Cooperation and Development (as cited by Health Canada, 1999c) considers a region to be rural if more than half of its population lives in communities with densities of fewer than 150 persons per square kilometre. Based on 1996 census statistics, 31.4% of all Canadians live in rural and remote regions. With an estimated 25 to 33% of the country's population living in remote and isolated areas, there is an obvious need to address rural considerations and perspectives when planning for medical and social services delivery (Health Canada, 1999c, np). Watanabe and Casebeer (2000) have recently described some of the unique health care issues that rural and remote Canadian communities face:

> The determinants of health, such as socioeconomic status, environment, gender, age/stage of development and culture, must be examined and analyzed through the lens of rural, isolated and northern, for their impact may differ or be magnified in such communities. (np)

Other characteristics that must be considered in the Western Arctic include the aboriginal component of the population, geographic isolation, and the definitions of proper or adequate health service. Combined, these factors can be expressed as a set of health states generating a specific set of health needs. Examples of needs that are unique to the region in question range from education on all-terrain vehicle roll-over prevention to diabetes prevention to Inuit and Dene communities.

Health Care in Canada's Western Arctic

Canadians are privileged to receive health care services through a publicly funded health insurance system established by the Canada Health Act of 1984. The act spelled out the criteria and conditions that provincial and territorial health services must meet in order to receive financial contributions from the federal government. The stated goal of the program is to ensure that all Canadians have reasonable access to medical services without direct charges, and access to health care that is comprehensive, universal, portable, and publicly administered (Health Canada, 1999b).

In sharp contrast, United States citizens must choose from a range of health insurance options (e.g., Medicare, Medicaid, and private and employer-supported plans), each with its own coverage and eligibility rules, and each with its own administrative layers that scrutinize and reject or pay medical bills on a case-by-case basis. The lack of medical insurance coverage—especially for the poor and a growing number of middle-income individuals and their families—has become a major political issue.

Despite its wealth and supply of highly skilled health care providers and advanced health technologies, a substantial percentage of the American public is denied access to these services. Disparities in availability, affordability, and accessibility are especially sharp in rural and remote areas (Knowles, 2000; Silveira & Winstead-Fry, 1997; Steiner, 1991).

Constitutionally, the administration and delivery of health care services is the responsibility of each of the provincial and territorial governments (Health Canada, 1999b). In 1998 the territorial government asked residents to make recommendations for sustaining and improving their health and social service systems in the Western Arctic. According to The Final Report of the Minister's Forum on Health and Social Services (GNWT, 2000b), residents of the Western Arctic have strong expectations of quick access to health care services when needed. The Canadian Medical Association (CMA) in its 2000 policy statement on rural and remote health care issues, stated its concern that "the health care infrastructure and level of professional support in rural and remote areas are insufficient to provide quality care and to retain and recruit physicians relative to community needs" (Canadian Medical Association Journal, 2000, p. 1047). As described in a previous section, the provision of health care services to this location is challenged by geography, climate, isolation, culture, the availability of local resources, and distances to hospitals of health care centers. Watanabe et al. (2000) have suggested that "these same characteristics can produce positive qualities, such as community identity, distinct societal supports and resiliencies"(np). Today there is considerable debate on the potential of promoting these positive attributes in non-rural communities.

There is growing evidence of a need to examine what constitutes appropriate heath care within locally available resources. For example, Lessard (1994a) has promoted a model of non-specialist perinatal care for women living in the Western Arctic. He noted that almost half of all prenatal care in the region is provided by community health nurses, and the other half by family practitioners. Obstetricians travel regularly to the outlying centres for consultation and teaching. Providing care closer to the patient's home demonstrates a rurally sensitive service.

Some researchers have pointed out that physicians in rural areas require broader skills and practices compared to their urban colleagues. Rural general practitioners often need enhanced skills to perform simple surgical procedures, address mental health issues, and provide neonatal care (Leduc, 1997; Rourke, 1997). Ideally, health care providers in rural and remote areas will have complementary skills that can be maximized to meet local needs (Lessard, 1994a). In many Western Arctic communities the number of care providers is limited, and therefore much of the responsibility for primary health care provision falls on the shoulders of nurses with advanced skills and knowledge. "As anywhere, nurses hold the fort, but in the NWT that means running hospital departments and remote nursing stations and practicing medicine in a way that leaves no room for trivializing contributions" (Jenkins, 1994, p. 21).

In a joint statement on health care reform issued in September 1998, the NWT Medical Association (NWTMA) and NWT Registered Nurses Association (NWTRNA) outlined a collaborative model for primary health care delivery in the territory.

The need for collaboration was increased due to recent changes that had been made in the administration of primary health care services in the Western Arctic. Regionalization and the loss of a central office ensuring uniformity in care delivery and management highlighted the fact that different territorial communities had different levels of primary health care expertise. The two organizations argued that such inconsistency increased the risk that some patients might receive services that fell below nationally accepted standards. To address this problem, the report's authors argued in favor of a community-based primary health care model that was both appropriate and economical for remote and isolated communities (NTMA/NWTRNA, 2000).

Section Summary

Themes identified in the literature on health care in remote and rural areas include:

1. No universally accepted definition of "rural" exists in Canada. The word is frequently linked with "northern," "remote," "isolated," "under-serviced," and "culturally diverse."

2. Defining rural and remote populations is a complex task that cannot be based solely on such quantifiable concepts as population density and distance from urban centers. Many researchers agree that any definition must include such factors as geography, climate, economics, social, and cultural dimensions.

3. Much of the literature on rural health care focuses on comparisons with urban areas in terms of physician availability.

4. Canadians are privileged to receive health care services through a publicly funded health insurance system that reduces financial barriers to health care.

5. The challenges of geographic and cultural isolation, finances, and human resources also highlight such positive rural qualities as community identity, societal support, and resiliency. The potential for transferring these attributes to non-rural communities is being discussed by researchers.

6. Ideally, the complementary skills of health care providers should be maximized to meet the needs of rural and remote residents. The community-based primary health care model currently used in the Western Arctic appears to be most appropriate and economical for such environments.

Culture and Health Care

The Western Arctic's aboriginal population makes it culturally unique compared to the rest of Canada, and so a discussion of culture is germane to any study of health care perspectives in the region. While this literature review focuses on aboriginal people in the Western Arctic, it is not the author's intent to minimize the importance or relevance of other cultures living in the NWT and what may be their own unique health care issues.

According to the Government of the Northwest Territories' Bureau of Statistics (GNWT, 2000), the 1998 NWT population was more than 50% aboriginal, including a diverse representation of the Dene, Metis, and Inuit groups.

Furthermore. according to the NWT Health Status Report (GNWT. 1999). "No longer is it [the NWT] a place inhabited by people whose background are either aboriginal or Western European. As with the rest of Canada. immigration is increasing from Asia and Africa" (p. 56).

The major change taking place in the country's ethnic mix is acknowledged in the Canadian Multiculturalism Act (1995). which commits the federal government to "a policy of multiculturalism designed to preserve and enhance the multicultural heritage of Canadians while working to achieve the equality of all Canadians in the economic. social. cultural and political life of Canada" (np). as well as "to recognize and promote the understanding that multiculturalism is a fundamental characteristic of the Canadian heritage and identity and that it provides an invaluable resource in the shaping of Canada's future" (np).

Yet the word "culture" remains elusive in terms of a universally accepted definition. Discussions of the concept are found in professional journals in the fields of anthropology. medicine. nursing. social work. and psychiatry. among others. Accordingly. the term "culture" refers to a shared identity based on such factors as common language. shared traditions. values. beliefs. attitudes. and ways of thinking. Lessard (1994b) describes it as a "way of life in which people deal with human beings in society . . . the language and the art . . . the way you raise your children . . . deal with health in a community. with economic development and spiritual needs" (p. 1578). In Smylie's (2001b) view. "The culture of a particular group of people could be defined as their world view and its expression in language. customs and art. Because world view is influenced by environment. culture is a dynamic entity" (p. 160).

Warry (1998) adds that "Culture is something that is enduring, while constantly transforming and changing" (p. 35), and Leininger (1994) reminds us that culture includes many facets of the way of life of people who share a common learned tradition which is passed on from one generation to the next.

Antone, Miller and Myers (1986) have asserted that cultural values and beliefs should transcend time and contribute to the uniqueness of a people; however, we are instead seeing the effects of sustained cultural oppression, often expressed in the ways that individuals treat themselves, their families, and their communities: "Holistically, culture should be viewed as a living dynamic, composed of all social institutions that ensure the transference of beliefs, values, language, and traditions. An indigenous person should not have to struggle for recognition, but simply be accepted" (p. 17).

Culturally Appropriate Health Care

There is overwhelming research support for the idea that aboriginal populations require culturally appropriate approaches to health care that may differ from those offered to other Canadians. Examples include the five-volume Report of the Royal Commission on Aboriginal Peoples (RRCAP, 1996) the results of extensive public hearings, community visits, expert consultation, commissioned studies, and literature reviews. Other sources of information on culturally appropriate approaches to health care have been published by the Canadian Medical Association (1994); Federal, Provincial, and Territorial Advisory Committee on Population Health (1999); Health Canada (1999a); Lessard, 1994b, 1995; and Smylie (2000a, 2000b; 2001a; 2001b).

Much of this literature promotes the idea of health care providers making the effort to understand the culture of their patients. Leininger's (1994) comment that "health professions are in an era of acquiring knowledge about a new dimension of a human being, namely, his culture" (p. 110).

In the Canadian health care system, physicians and nurses are frequently the first or only contact for aboriginal patients: failure to understand cross-cultural communication principles and the special needs of individuals from other cultures can put relationships between care providers and their patients in jeopardy (Hamilton, 1996; Masi, 1992). Therefore, Smylie (2000a; 2001a) encourages physicians and other health professionals to seek opportunities for learning about multicultural health care issues, arguing that " [i]n forging a balanced and positive health care practitioner-patient relationship, it is essential to understand the heritage context of the aboriginal patient in order to negotiate the chasm and find common ground" (p. 1057).

Ethnostress

Ethnostress, which occurs whenever cultural beliefs or identities are disrupted, is the negative experience felt when members of different cultures interact. Ethnostress is centered in an individual's self-image and sense of place in the world (Antone et al., 1986). There is a substantial body of research on what occurs when First Nations people assimilate (or attempt to assimilate) into a western-dominated social structure that has actively oppressed and eroded several generations of aboriginal North Americans (Alfred, 1999; Antone et al., 1986; Berry, 1980; Ross, 1996; Sinclair, 1997; Smylie, 2000b).

Berry (1980) preferred the term "acculturative stress" to describe the response of many aboriginal people to interacting with other cultures, and pointed out its impact on other ethnic groups as well.

The author stated the stress sources can be economic; social and personal isolation; negative, threatened, or actual violence; and moving from smaller to larger communities.

Language

The literature also suggests a strong link between language and cultural identity. During the RRCAP hearings, an aboriginal woman named Dawna LeBlanche noted the devastating impact that government policies have had on their indigenous languages: "The elimination of language was the prime target for the government and the missionaries, knowing full well that without a language we would no longer be a distinct people as language is culture and culture is language" (RCAP Hearings, 1996, np). The issue of lost aboriginal languages is addressed in Health Canada's Second Diagnostic on the Health of First Nations and Inuit People in Canada (1999a):

> In the last century or so ten aboriginal languages have become extinct and at least a dozen or so are on the brink of extinction. As of 1996 only 3 out of Canada's 50 aboriginal languages could be considered secure from the threat of extinction. (p.23)

Furthermore, the NWT Health Status Report (GNWT, 1999) points out that "English is the most common home language in the Northwest Territories, with almost 90% of the population reporting it as their home language in the last census. Native languages as a whole were the next most common" (p. 57).

Even though indigenous linguistic retention varies among aboriginal populations, its role in cultural and community revitalization cannot be underestimated (Antone et al., 1986; Dorais, 1995; Leininger, 1994); once a language dies, cultural transmission becomes increasingly difficult. One example of the successful retention of a language is found in the NWT where many Inuit communities still use the Inuktitut language for daily transactions (Smylie, 2000b). In a study examining the relationship between language, self-definition, and cultural identity among Inuit populations, Dorais (1995) found that the "importance of Inuktitut lies primarily in its power as an agent and symbol of identity" (p. 297).

In order to ensure that aboriginal patients are part of an informed decision-making process regarding their health, they must fully understand their options and feel comfortable enough to ask questions. Much of the literature on the subject of language and health care advocates the use of trained interpreter services and cautions against the use of untrained staff, relatives, or other patients (Bouvrette, 1994; Lessard, 1994b, 1995; Masi, 1992; Penny, 1994; Smylie, 2001b). Based on these suggestions, the SRHB has access to medical interpreters fluent in nine aboriginal languages and dialects. The interpreters also assist in the provision of traditional meals, appropriate accommodations advocacy services, and transportation.

Respect

According to Smylie (2001b, p. 158), "Respect is the cornerstone of many aboriginal philosophies." The aboriginal psychiatrist Clare Brant (1990) described the "ethic of non-interference" as a means by which aboriginal people show respect for another person's independence, and identified other primary ethics as those of non-competitiveness, emotional restraint, and sharing (that is, putting family and community success ahead of individual needs). Brant also recognized four secondary ethics: a) an emphasis on doing things "when the time is right" rather than by the clock, b) shying away from public expressions of praise, c) ordering social relations by a series of complex but unspoken rules, and d) teaching by modeling rather than direct instruction. It is especially important for health care providers to keep the significance of family and community in mind when working with aboriginal patients. Whereas children in western cultures are raised within nuclear families, aboriginal adults are the products of influences from an entire community in addition to the many members of an extended family (Antone et al., 1986; Smylie, 2001b).

Traditional Healing

Many aboriginal Canadians are looking to their cultural pasts in an attempt to recapture traditional knowledge. This is part of a general movement toward self-determination and self-government. A central tenet of this process of cultural and community revitalization is renewing traditional healing practices, ranging from the use of herbal medicines and other physical remedies to the promotion of psychological and spiritual well-being via ceremonies, counseling, and the accumulated wisdom of elders (Lessard, 1994b; Smylie, 2001b).

Unfortunately, little research has been done on the extent to which aboriginal people in the Western Arctic are still using traditional healing practices. Nevertheless, the final report from a forum organized by the NWT Health and Social Services Minister contains a recommendation that health care providers and government officials recognize the status of traditional aboriginal healers (GNWT, 2000b).

Cultural Attitudes and Disclosing Cancer

Most Native North American languages do not have a word for cancer. Cobb (1999, p. 165) has written that many indigenous peoples use a phrase translated as "a sore that does not heal." The Dene and Metis languages have no specific word for cancer, and Inuktitut speakers use a term meaning "the disease for which there is no cure" (Corriveau, 1997 p. 5). Inuit and Dene elders perceive a cancer diagnosis as a death knell, with most fearing that they will never return to their homes if they are sent south for treatment (Corriveau, 1997). Such an attitude raises the important question of disclosure. In a study of Native American, European, and ethnic American cancer patients, it was found that many cultures consider complete, detailed disclosure undesirable in the case of cancer (Mitchell, 1998). The author further described cultural differences in terms of diagnostic or prognostic disclosure and the use of euphemisms by physicians when giving cancer diagnoses. Mitchell's final suggestion was that health care providers should try to find out their patients' preferences for disclosure and their wishes for family involvement.

Where Do We Go From Here?

The final report from the NWT Forum on Health and Social Services (GNWT. 2000b) shows that the GNWT has commissioned four major reviews of its health care system during since 1996. and that many of its 200 recommendations have yet to be acted upon. In their cover letter to the Minister of Health and Social Services. the report's authors clearly stated two recommendations: first. "no more reviews. studies. [or] reports are needed"; second. "action is wanted today, not tomorrow." In spite of their clear message. the NWT Health and Social Services department commissioned still another major review of the NWT health care system in November 2000.

The authors' comments underscore the idea that Canada's political will is about to be tested as it makes policy decisions regarding aboriginal health care. As Postl (1999) argues:

> The studies have been done. and it is time to act . . . to do otherwise is to risk the perpetuation of ill health in Canada's First Nations. Do we really want to show off our national character under such a dim light? (p.1656)

Section Summary

The most important themes identified in the literature on rural and aboriginal health care issues were:

1. Compared with the rest of Canada, the Western Arctic is culturally unique due to the proportionately larger population of aboriginal people. The federal government has made a commitment to preserving and promoting the multicultural heritage of Canadians through the Multiculturalism Act.

2. The term "culture" refers to many concepts, mostly centered around a shared identity based on such factors as common language, shared traditions, values, beliefs, attitudes, and similarities in thinking and being.

3. The Canadian health care system has many barriers for Aboriginal people seeking health care. The effects of disruptive cultural oppression are often expressed through the ways in which individuals treat themselves, their families, and their communities.

4. There is a documented need for culturally appropriate approaches to be incorporated into health care systems serving aboriginal populations.

5. There is a strong link between language and cultural identity. Aboriginal people should receive health care in their own language, with trained interpreters and patient advocates.

6. Respect is an important cornerstone of aboriginal belief systems.

7. There is increasing movement towards recognizing traditional Aboriginal healers and their methods.

8. Health care providers should try to become aware of how or if their patients would like to be informed of a cancer diagnosis and how involved they want their families to be in terms of treatment decisions.

9. No more reviews, studies, or reports are needed. Action is wanted today, not tomorrow.

Client-Centred Care

Many health care organizations refer to patients/clients as the focus of care in their mission, vision, and values statements. Accordingly, client-centred care (that is, paying attention to clients' perspectives) has become increasingly important (Gerteis, Edgman-Levitan, Daley & Delbanco, 1993). The current literature contains several variations of this idea and related terminology, including: "client-centred," "client-focused" (Law, Baptiste, & Mills, 1995; Rogers, 1951; Sherer, Anderson & Lumsden, 1993), "patient-centred" (Toop, 1998), and "customer focused" (Ford & Fotler, 2000).

A brief examination of SRHB documents show that even though the terms "focused" or "centred" are not used explicitly, "persons" are viewed as the focus of care. According to the board's 2001-2004 business plan, the management team's values statement "recognize[s] our customers as the focus of our work" and acknowledges "respect is the key to building strong partnerships" (SRHB, 2001b, p. 2).

In addition, a theme identified throughout the SRHB Hospital Quality Management Program (1998) is that the voice of the "patient" is an integral partner in the quality management cycle.

In the mid 1940s and 50s, a client-centred theory of personality and behavior was developed by Carl Rogers, an American psychologist. In his book entitled Client-Centered Therapy (1951), Rogers described a shift from a "directive" approach to therapy (in which therapists attempt to deliberately steer their clients in a specific direction) to a "non-directive" approach. He argued that therapists should instead simply act as assistants and as safety nets for clients who direct their own progress. He expressed his faith in the ability of individuals to recognize their own solutions in this comment: "When a client uses her own voice to describe her problem in a supportive environment, she can see that problem and find options for solving it herself" (1951, p. 28).

Rogers (1951) felt strongly that people tend to move in a direction of growth and healing, based on their individual capacities to find their own answers. Believing that such a tendency can be reinforced in an accepting and trusting environment, according to Rogers (1951) the key role of client-centered therapists is to listen and attempt to understand their clients' viewpoints, then check to make sure their understanding coincides with their clients' perspectives, all the while treating them with the utmost respect. In his view, successful therapists possess self-awareness and self-acceptance.

"Rogerian therapy" is the name commonly used today to describe a client-centred approach. This theory has been accepted and adopted by practitioners in many health and social services professions, including nursing (Ferguson-Pare, Bourpret, Bernick, Buchannan, Cabico, King & Rivera, 2000; Tranmer, 2000), medicine (McWhinney, 1998; Toop, 1998), occupational therapy (Law et al., 1995), and administration (Ford & Fottler, 2000).

In biological medicine, a client-centered approach has altered the way in which diagnoses are made. Until the latter part of the twentieth century, any understanding of what illness meant to a patient tended to be an afterthought—something added on after the diagnostic task was completed. As McWhinney (1998) notes, many health care providers now recognize their patients often have problems which are not entirely biomedical, or with diseases requiring an understanding of their contexts before making appropriate management decisions. He believes a client-centred approach gives patients "permission to dwell on the real issues" (p.1808) associated with their medical problems while simultaneously giving their physicians a better understanding of their patients' emotional and physical statuses. Toop (1998) refers to this special interaction between a doctor and patient as a "sustained partnership" (p. 1883). Suchman (1994) coined the term "biopsychosocial care," which he said rests on two basic principles:

> First, medical care must be firmly grounded in the patient's subjective experience of illness . . . and second, the patient and the clinician must be collaborators, sharing responsibilities for defining goals and problems, making decisions, and carrying out treatment plans. (p. 544)

In medical school and other professional training programs, care providers are encouraged to be sensitive to the "human" aspects of health care, listening attentively to their patients' concerns, perspectives, and hopes. Research has demonstrated that the human approach has the potential to empower and motivate those patients to take an active role in their own care regimens (Gerteis et al., 1993; McRae, 2001; Tranmer, 2000). Sherer et al. (1993) believe the concept of care continuity is important in patient-centred relationships, arguing that the promotion of trust is a core part of any relationship between a care provider and patient. Doing so encourages patients to raise issues, to confide at a deeper level, and to ask questions that might otherwise be held inside.

In the area of geriatric care, Ferguson-Pare et al. (2000) argue that practicing client-centered care "assist[s] in honoring the person hood" (p. 31) of elderly hospitalized patients, adding that it is important to "take time and, in fact, slow down the pace of the hospital experience and to understand that the experience of time changes with aging" (p. 31). Doing so demonstrates respect and creates a supportive environment.

In the area of occupational therapy, Law et al. (1995) introduced a model of client-centered care which fits that specific profession. Their proposal consists of six concepts: a) the provision of autonomy and choice, b) partnership and responsibility, c) enablement, d) contextual congruence, e) accessibility and flexibility, and f) respect for diversity. Similar to the therapist's role described by Rogers (1951), Law et al. (1995) believe care providers must remain aware of their own values and needs, and refrain from imposing them on their clients.

The Picker Institute for Patient-Centered Care in Boston specializes in health care assessment and improvement strategies based on patient perspectives. Gerteis et al. (1993) summarized the institute's work and overall approach in a book entitled 'Through the Patient's Eyes' . Using focus groups, survey data, and site visits, the authors described what American patients view as the major problems in the country's health care system. The eight areas identified as requiring immediate reform were a) respecting patients' values; b) understanding patients' preferences and expressed needs; c) coordinating and integrating patient care; d) providing clear information and improving communication and education efforts; e) providing physical comfort and emotional support, while making efforts to alleviate anxiety and fear; f) improving the involvement of family and friends; g) paying greater attention to care transitions and continuity; and h) improving access to care. The authors concluded that the word institution (i.e., hospitals) need not be synonymous with impersonal.

Ford and Fottler (2000) have recently described the trend of hospital administrators recognizing the need to ensure a positive health care experience for their "customers", one that goes beyond positive clinical outcomes. They report that in health facility management and accreditation, there is currently a shift in focus from process improvements to measuring process results.

Ten key areas the authors identified as benchmarks of successful customer-focused health care organizations are: a) service quality and value defined by the customer; b) full participation by patients that adds value to their health care service experience; c) a customer-focused culture; d) selecting and training customer-focused employees; e) motivating employees to be customer-focused; f) designing a seamless customer-service system; g) managing waiting times; h) creating a setting based on customer expectations; i) measuring all aspects of the service experience; and j) making a commitment to continuous improvements.

In a report prepared for the American Hospital Association, the Picker Institute (1996) stated that clients who had entered the American health care system as hospital patients ranked their desire for compassionate care providers higher in importance than food menu choices or reception staff politeness. In a recent interview, Susan McRae of the Picker Institute commented:

> Listening to the patient's experience used to be thought of as soft stuff. This is simply not the case. People need to look at the literature and realize that going deeply into the needs that patients define as important can be an important way to reorganize and improve our health care system. These kinds of approaches have a tremendous impact not only on the patients, but also on the clinicians, on the system and on cost. (np)

Section Summary

The common themes found in the literature on cultural issues in health care include:

1. Client-centered care is an approach that consciously adopts a patient's perspective.
2. According to Rogers (1951), client-centered therapists listen attentively in order to better understand their clients' points of view, check their understanding with their clients if unsure, and treat their clients with the utmost respect.
3. Relationships should be allowed to develop so as to promote trust—a core part of interactions between care providers and their patients. Sustained relationships (and the trust that results) encourages patients to raise issues, to confide at a deeper level, and to ask questions that might otherwise be held inside.
4. Researchers at the Picker Institute have identified eight areas of patient care that require immediate reform: a) respecting patients' values; b) understanding patients' preferences and expressed needs; c) coordinating and integrating patient care; d) providing clear information and improving communication and education efforts; e) providing physical comfort and emotional support, while making efforts to alleviate anxiety and fear; f) improving the involvement of family and friends; g) paying greater attention to care transitions and continuity; and h) improving access to care.

Supportive Care

In reference to cancer, the term "supportive care" has traditionally been used to describe aspects of care which directly support patients' anti-cancer therapies (e.g., antiemetics, transfusions, and antibiotics), or the care of symptomatic patients with advanced diseases (Levy, cited in Whelan, Mohide, William, Tew, Sellick, Gafni & Levine, 1997). The requirements associated with cancer diagnosis and treatment are very complex, including physiological, emotional, psychological, spiritual, social, and economic changes on the part of patients and their families (Northouse; Kristjanson & Ashcroft as cited in Fitch, 2000). In recognizing the need to provide more comprehensive service to all patients living with cancer, Fitch (1994), expanded on previous definitions of supportive care:

> Supportive care is defined as . . . the provision of necessary services as defined by those living with or affected by cancer to meet their physical, social, emotional, informational, psychological, spiritual, and practical needs during the pre-diagnostic, diagnostic, treatment, and follow-up phases of cancer care, encompassing issues of survivorship, palliation and bereavement. (p. 41)

In its final report on the Needs of People Living with Cancer, the Canadian Cancer Society (1992), compared the major psychosocial problems and needs of patients living in Ontario and on Prince Edward Island. The subjects included patients who had recently been diagnosed with cancer, those undergoing treatment, and those being monitored.

The three categories of patients identified as having the greatest number of unmet needs were those living with active diseases (particularly in the advanced or palliative stages); those whose diseases interfered with family, economic, and work lives: and those living in remote and rural areas. The most highly ranked needs cited in the report were for prompt medical attention, information, emotional support, employment, and pain management. The authors acknowledged that their study under-represented the needs of cultural minorities, including Aboriginal people.

In another report, published by the Ontario Cancer Treatment Research Foundation and entitled 'Providing Supportive Care for Individuals Living with Cancer', Fitch (1994) identified six needs categories for individuals living with cancer: physical, emotional, informational, psychosocial, spiritual, and practical. In acknowledging that supportive care is not the domain of any single profession or group of individuals, its authors called for leadership at the regional and provincial levels in implementing a formal, supportive care program based on certain basic standards.

The report recommends leadership at the regional and provincial level to support implementation of a formalized supportive care program based on basic standards for supportive care of cancer patients as listed below.

All individuals will:

1. Receive ongoing supportive care assessment,
2. Have the opportunity to be referred to an appropriate supportive care resource,
3. Have the opportunity of self-referral to supportive care resources,
4. Have access to understandable, relevant information regarding the medical, practical and emotional aspects of their cancer and its treatment; and
5. Receive supportive care that is relevant to their needs and sensitive to their age, gender, language, culture, sexual preference, religion and economic status (Fitch, 1994, p. 15).

The Stress of Unmet Needs

There are increasing public expectations that all cancer patients will receive appropriate support throughout their experiences with the disease, to the degree that when those needs are not fully met, substantial psychosocial distress occurs (Fitch, 2000). Whelan et al. (1997) studied one sample of cancer patients and reported that a) more than 40% reported low energy, a worried outlook, difficulty sleeping, and coughing; and b) 35% were identified as psychologically distressed. After surveying a separate sample of cancer patients, Ashbury, Findlay, Reynolds and McKeracher (1998) reported that 71% rated both fatigue and anxiety as their main concerns, 53% identified depression, and 48% sleep disturbances.

Fitch (2000) reviewed a number of studies on the same subject (including Cassileth et al., 1984; Derogatis et al., 1983; Farber et al.,1984; and Holland and Rolland, 1989) and identified the prevalence of significant psychosocial distress for mixed groups of outpatients with cancer. However, she also cautioned that "The presence of psychosocial distress does not in itself reveal the reason for that distress. The reason usually needs to be uncovered through dialogue with the individual" (p. 40).

Information

A repeatedly identified theme in the literature is the need on the part of patients for understandable information. Ashbury et al. (1998) found that "92% [of all cancer patients] felt it very important to have information about cancer treatments" (p. 302). Whelan et al. (1997) suggest the information needs of newly diagnosed cancer patients are much greater than those of patients undergoing active treatment or follow-up and palliative care. In the early stages, patients seem to be more concerned about treatment and disease-specific information than procedural issues. The Canadian Cancer Society (1992) found that the majority of cancer patients felt the greatest need for information and support just before surgery. Fitch (2000) adds that while emotional and spiritual support may remain constant throughout the course of an illness, pain and symptom control issues grow in importance as the disease and treatment progress. Whelan et al. (1997), in suggesting that research focus on understanding the information needs of patients as they move through the various stages of cancer, argue that doing so can assist in the planning of supportive care services.

Providing Supportive Care

Fitch (2000) also reminds us that while cancer patients "receive treatment in hospitals, outpatient clinics and physicians' offices . . . they live with their cancer at home in their own community" (p. 42). Whelan et al. (1997) reported that "Despite the fact that the vast majority of patients had identified ongoing problems or concerns, only a limited number reported utilization of community resources. However, most patients identified someone they could depend on" (p. 1523).

Throughout their cancer experiences, patients interact and communicate with many health professionals, but patients frequently place equal value in interactions with other individuals who have experienced cancer. "Recent studies of peer support programs have described the benefits patients feel from their interactions with other cancer patients, whether one-to-one, in a group or over the telephone" (Gray as cited in Fitch, 2000, p. 42).

Current Status of Supportive Care Delivery

In all, a review of the literature in this area reveals numerous gaps in the coordination and delivery of services and programs designed to support cancer patients. Ashbury et al. (1998) suggest that "the current understanding of cancer patients' experiences and needs is limited and the existing information is insufficient to guide the development of policies and programs intended to meet their needs" (p. 299).

Research and information gaps identified by Fitch et al. (1994; 2000) and Gray et al., as cited in Fitch (2000) include a) access to understandable information; b) treatment options and possible side effects; c) access to community resources and practical aids; d) access to peer support and to pain and symptom management; and e) access to professional counseling.

Several Canadian-based studies support a comprehensive, integrated cancer care delivery system which incorporates supportive care services (Canadian Cancer Society, 1992; Fitch, 1994; Health Canada, 2000b). Yet it is well known that no single organization or institution has the resources or jurisdiction required to address the challenges of providing comprehensive services to cancer patients in Canada. Recognizing the need for a coordinated strategic approach, Health Canada, the Canadian Cancer Society, the National Cancer Institute of Canada, the Canadian Association of Provincial Cancer Agencies, the Supportive Care/Cancer Rehabilitation Work Group, and six other agencies are working together to develop a Canadian Strategy for Cancer Control. The first draft report, published under the name of Health Canada (2001b), reinforces much of the same findings and recommendations found in the Ontario Cancer Treatment Research Foundation's 1994 report.

Section Summary

The themes identified in the literature on supportive care include:

1. The diagnosis and treatment of cancer brings a wide and varying range of needs. Along with the physiological changes for the patient there may be emotional, psychological, spiritual, social, and economic changes. Addressing these changes may generate numerous challenges for the patient, family and friends.

2. Cancer patients will experience a varying degree of needs at different stages as they progress along the cancer continuum. More research is needed to determine the patterns of supportive care needs over time and the resultant utilization of services.

3. Ultimately, supportive care seeks to preserve and improve the quality of life, autonomy and dignity of those living with, or affected by cancer. Despite calls for a comprehensive integrated cancer care delivery system progress has been slow. Commitment and strong leadership will be required at all levels to develop an integrated, collaborative approach to providing coordinated cancer care services.

CHAPTER 3 - RESEARCH METHODS

The purpose of this study was to learn about the experiences of patients living in extremely remote areas during an emotionally charged period in their lives: living with cancer. Geography is an additional source of anxiety for these residents of Canada's Western Arctic region, where access and availability to services are considered a challenge. By interviewing cancer patients and care providers, my hope was to discover meaning in their experiences, and perhaps identify ways to improve the services provided by the Stanton Regional Health Board (SRHB) Medical Clinics.

This report is based on the results of an inductive, qualitative action research project whose focus was the quality of an experience, as opposed to quantifying the experience through statistical manipulation. Qualitative research allows for small sample sizes; data is gathered through interviews, participant observation, and soliciting written or oral descriptions of lived experiences. As one form of qualitative research, "action research" is described by Calhoun (quoted in Stringer, 1996) as "disciplined inquiry which seeks focused effort to improve the quality of people's organizational, community, and family lives" (p. 9).

Palys (1992) describes the main objectives of a research project as exploratory, descriptive, relational, or explanatory. Initially, this research was exploratory—that is, I tried to become familiar with the perspectives of the patients and to gain insights into their lives.

As well, the project also had a descriptive aspect in the form of my attempts to accurately portray their experiences. Epistemologically, those descriptions focus on the patients' frames of reference and the perspectives—unique or commonly held—that are specific to their experiences.

The study was conducted using Stringer's (1996) suggestion to "look, think and act" (p. 17) at every stage, and to view the action research method as "a routine of continually recycling sets of activities" (p. 17). The cycle begins with the "look" stage, during which the researcher gathers relevant information and starts to build a picture of the situation. The researcher then begins to interpret and explain the data during the "think" stage, and for the "act" stage, uses the data and interpretations to create a plan for addressing the major issues that have been identified. Stringer (1996) also noted, "As participants move through the various stages they will continually review (look again), reflect (reanalyze) and re-act (modify their actions)" (p. 17). I found this to be particularly true during this study, and soon came to realize that looking, thinking, and acting were all part of building a foundation, in which reviewing, reflecting, and re-acting constituted a cyclical subset.

I chose this particular method of inquiry for three reasons:

1. I felt that action research could provide an opportunity to increase my personal knowledge, as well as my knowledge of SRHB and the community I live and work in. As a nurse leader at the Health Board's clinics, I have many chances to incorporate such knowledge into my job and work environment.

This is precisely as Dick (1999) noted in his comment that "Action research lends itself to use in work or community situations. Practitioners, people who work as agents of change, can use it as part of their normal activities" (p. 17).

2. I felt that action research would help me identify ways in which the services that SRHB provides to cancer patients in particular and all patients in general could be improved. Stringer (1999) defines the primary purpose of action research as "a practical tool for solving problems experienced by people in their professional, community or private lives" (p. 16). There is little in the way of written information on the experiences and perspectives of cancer patients living in the Western Arctic. In light of the large percentage of Canadians who live in rural and remote areas, I felt that interviewing cancer patients in this region and learning about their challenges might be generalizable, and therefore be used to improve health care services in other parts of the country.

3. Action research requires a collaborative approach that views participants as equal and full partners in the process. It also takes into account the impact of research activities on the lives of the people involved (Stringer, 1996). As a nurse leader, I find these concepts to be ethically satisfying.

Creating the Research Question

I did not have a precise research question in mind when I began this study. I wasn't quite sure where to begin, although I felt certain that I had unanswered questions about the services provided by SRHB to cancer patients in its catchment area. I found support from Dick (1999), who believes that:

> One of the key principles of action research is to let the data decide. At each step, use the information so far available to determine the next step . . . the whole purpose of action research is to determine simultaneously an understanding of the social system and the best opportunities for change . . . the question arises from the study. (np)

Stringer (1996) describes the gathering of preliminary data and the determination of whom to work with as a "constructive, meaning-making process" (p. 40). My data collection process began with the identification of key contacts and stakeholders inside and outside the organization. In September 2000 I began to familiarize myself with the SRHB-based and community services that are available to cancer patients. I let people know that I was working on this project, and began to interact with individuals who care very much about cancer services in the far north. Inside SRHB, I met with a physician specialist, several nurses and medical interpreters, a hospital social worker, a chemotherapy nurse, and the Director of Patient Care. I then spoke with several cancer patients with extensive experience navigating through the health care system.

Outside of the immediate community, I discussed the study with representatives from the Canadian Cancer Society, the NWT Breast Health Breast Cancer Action Group, the Status of Women, Cansurmount, and the Cancer Registry for the NWT and Nunavut.

There is clearly a significant amount of valuable work being done on behalf of cancer patients, both within SRHB and in the Yellowknife community. Unfortunately, the impression I got from my discussions with the individuals doing this work is that their efforts are, for the most part, uncoordinated. Nevertheless, I was deeply impressed by the level of their commitment, which gave me inspiration to move forward with this study. My feelings were reflected in a comment made by Ronna Jevne (2000), a psychologist and founder of the Hope Foundation of Alberta, in her "Credo of Hope":

> I have a vision that caregivers would share a strength—a strength that comes only from a common purpose, that comes from belonging to a community of people who believe that caring makes a difference, that custodians matter as much as physicians, that volunteers have a place beside nurses, that letters and titles matter less than kindness. (np)

In October 2000 I began meeting informally with the nursing staff and physicians of the SRHB medical clinics to inform them of my proposed research study and to cultivate their support. Because these professional care providers develop close relationships with their cancer patients, their assistance was considered essential to this research. These informal meetings provided suggestions and feedback, and potential leads for participants.

After receiving initial support from the people I work with on a daily basis, I made the effort to keep them informed of my progress during regular program meetings, SRHB staff meetings, and informal conversations.

I also approached the SRHB Medical Director to ask that the Health Board serve as an organizational sponsor for this study and received approval. As the individual responsible for all of the SRHB physician specialist programs, his support was considered vital to the study's success. As a member of the senior management team, he presented my proposal to his fellow directors and kept them informed of my progress. As the author of several journal articles, he understands the process of being published and is supportive of on-the-job research and life-long learning. He has a reputation for being passionate about patient care quality and for being interested in trying new methods for improving patient services.

In November of the same year I was invited to participate with representatives of SRHB and the Alberta Cancer Board (ACB) in a meeting sponsored by SRHB. This meeting was part of an informal link between the two agencies that was developed to support the Health Board's chemotherapy program. The contacts I made at this meeting led to introductions to the director of the Alberta Aboriginal Cancer Strategy Initiative for ACB, the co-coordinator for the ACB Community Contact Program, and the patient advocate for the Cross Cancer Hospital in Edmonton.

I was therefore given the opportunity to learn about the experiences of Western Arctic patients who must move temporarily to that city for advanced cancer care services (as mentioned earlier, a formal cancer program is not available at SRHB).

Using this time to set the stage for this study allowed me to learn more about the cancer services available to Western Arctic residents, to cultivate positive working relationships with key stakeholders, and to establish a supportive environment in which to conduct the research. After gaining a better understanding of the NWT health care system and cancer services, I could formulate a research question that had greater potential for effecting change. That question became:

> From a patient's perspective, what factors contribute to the effectiveness of services offered by the Stanton Regional Health Board Medical Clinics to patients living with a diagnosis of cancer in Canada's Western Arctic?

Ethical Approval

In keeping with Royal Roads University (RRU) and SRHB policies on research involving human subjects, formal applications were made to the Ethics Committees of both institutions. In giving its approval, the SRHB committee emphasized the need to be sensitive to the potential distress associated with recalling past experiences. As a registered nurse, I felt confident in my ability to recognize signs of emotional discomfort.

With the help of the SRHB Medical Clinics staff, I developed a list of internal and external resources for assisting study participants should such an event occur. Both applications were approved in January 2001.

Building the Picture: "Look"

1. **Planning for interviews**. The two types of interviews used for data collection in this research were one-on-one interviews with cancer patients and focus group sessions with care providers. The need for the second method was not obvious to me at the beginning of this study. Not until I completed my initial round of data collection did I recognize the benefits of gathering information from those care providers who most often listen firsthand to accounts of patient experiences. The information gleaned from the focus groups validated what I heard during one-on-one interviews and what I read during the literature review phase.

2. **Preparing the questions**. I consulted with nurses, physicians, and other care providers before writing my questions for the interviews and focus group sessions. During this process it became clear that the patients' experiences of navigating through the health care system were of great value to this study, even though the primary focus was on their experiences with the SRHB medical clinics. As I will explain in Chapter 4, the two clearly overlap. The interview and focus group questions were pre-tested with my sponsor and the SRHB Ethics Committee.

   Modifications (mostly simplifying the questions and making sure that they were opened-ended and not leading) were made based on the feedback I received.

3. **Participant selection**. Palys (1992) suggests that exploratory researchers should favor a "strategic sampling of insightful informants . . . such as people who are very familiar with a particular situation" (p. 82). Based on this advice, patients who had received services from SRHB medical clinics during the past three years but not within the last year were invited to participate in the study. It was felt that this time frame was reasonable for the patients to have reflected on their experiences, but not so long that they would have forgotten some of the details. For the participant sample, the average number of years of receiving cancer-related medical services from SRHB was 5.7 years.

Invitations were extended to Western Arctic residents who were considered representative of the geographically and culturally diverse population in the SRHB catchment area. Nurses working in various SRHB specialist programs identified potential participants. Initial contacts were made by telephone when booking a patient's next appointment or in person at the clinic. If a patient expressed an interest in participating or wanted more information, the nurse made arrangements for me to contact the individual; in a few cases, the patient contacted me directly. Five participants heard about my study from other sources—for example, a local cancer support group or other patients—and called me directly to volunteer. I felt the need to decline the offer of three patients with whom I had already spoken about local cancer services, feeling that these conversations may have biased my views.

Once initial contact was made, I spent time describing the study to potential participants, answering questions, and confirming their interest in volunteering. Whenever possible, interviews were scheduled to coincide with participants' medical appointments.

This was possible in all but nine cases: three participants requested home interviews and six were interviewed in my office at times that were not associated with their other SRHB appointments. An extra 30 minutes was scheduled for interviews with the four aboriginal participants who required medical interpreter services to ensure that they understood the purpose of the interview, since these participants were not given written information packages prior to the interview session. All other participants were personally given or mailed an information package which included:

a) a letter of invitation explaining the study purpose, the use of the data, the provision of confidentiality, and the option to withdraw from the process at any time without impacting their health care services (Appendix A1);
b) a copy of the consent form they were to sign prior to the interview (Appendix B1, B2); and
c) a copy of the interview questions (Appendix C1).

Of the 34 patients interviewed for this research, 38% (13) were male and 62% (21) female. According to the 1996 Statistics Canada Census, the NWT population at that time was 39,670, with 20,465 (51.6%) male and 19,205 (48.1%) female. The age range for female patients was from 35 to 62, and for male patients from 41 to 57. The study's ratio of regional to local patients was 65% to 35%. Of those 22 patients from outlying communities, only half had road access to Yellowknife; the other half required air transportation. Medical interpreters were required for four participants.

The two aboriginal languages used in these interviews were Dene and Inuit. All of the participants in the study had been diagnosed with cancer; 72% of the female patients had breast cancer and 31% of the males had bowel cancer. Other cancer sites included prostate, stomach, and lung.

Table 1 presents a general demographic profile of the study sample, which included five ethnic categories, and which was considered representative of the regional population. According to Statistics Canada's 1996 census, the largest ethnic group in the NWT is the Dene.

Table 1. Ethnic Distribution of Interview Sample

Sample	Dene	Metis	Inuit	Caucasian	Other	Total
Male-regional	4	1	1	3	--	9
Male-YK	1	--	--	3	--	4
Female-regional	4	4	3	2	--	13
Female-YK	1	--	--	5	1	7
Total	10 30%	5 15%	4 12%	13 40%	1 3%	33 100%
Census	27.8%	9.3%	10.2%	51.8%	0.8%	

Interviews

Since cancer is a very personal and sensitive topic, I had to be mindful about interviewing participants in an environment they considered safe and comfortable. I felt that my office provided such an environment, and its proximity to other SRHB facilities made it convenient for patients who had other appointments; however, all participants were given the option of choosing an alternate location. Interviews with 34 patients were held between February 5 and March 2, 2001. Thirty-one interviews were conducted in my office and three at patients' homes.

The first fifteen minutes of each interview was used to develop rapport with the participant, usually sharing coffee or tea and social conversation. An additional 20-30 minutes was spent discussing the information package with those whom I had not yet discussed the contents, or for those needing medical interpreters. To all participants, I explained the purpose of my study, reviewed the written information, and answered questions. I emphasized both the need to understand their experiences from their perspectives, and the value of their participation. I discussed my reason for audio taping the sessions and the need for signed consent forms. When participants appeared to be comfortable with the information and after they had signed their consent forms, I asked their permission to turn on the tape recorder and to start the interviews. Interviews lasted from forty minutes to two hours and ten minutes.

As suggested by Palys (1992) and Marshall and Rossman (1999), a semi-structured interview style was used to create a sense of informality and to promote rapport.

All participants were asked the same six prepared questions (Appendix C1), but in ways that suited the patients' individual understanding and situations. Those questions focused on the patients' thoughts and feelings about being diagnosed with cancer while living in a remote area, and their experiences with the health care system--especially with SRHB. Most of the participants seemed pleased to share their experiences. Several of the aboriginal elders were very brief in their responses, which I had anticipated based on my experience with other elders as a nurse; however, to my surprise, a few aboriginal elders provided rich, detailed, and heart rendering accounts of their personal experiences.

The advice from the SRHB Ethics Committee was well founded. Recalling certain aspects of their experiences brought up a lot of emotions in some participants. Stringer (1996) had also emphasized the need to be aware of participants' needs, stating that "Facilitators should be constantly sensitive to the need to provide affirming comments to people engaged in research activities, not in a patronizing or mechanical way, but authentically and specifically" (p. 106). I therefore looked for moments when I should give support, an affirmative nod or smile, a tissue, a cup of tea--or remain silent. In the few instances where I felt a participant might benefit from SRHB or community resources, I was quick to offer contact names and telephone numbers, and followed up with a phone call a few days after the interview. This conveyed the genuine concern I felt for these study participants.

In addition to audio taping the interviews, I also kept handwritten notes. Participants were offered opportunities to review the transcripts of their own interviews to ensure that the information was accurate.

Five participants requested to see their own transcripts, from which they did at a follow-up meeting two weeks later; the other twenty-nine indicated that they would wait to read the final document. Each of the five participants who reviewed their transcripts gave their approval without changes; three accepted my offer to let them review my draft recommendations before submitting the final report.

Focus Groups

The success of focus group interviews depends on interaction among the participants. As Morgan (cited in Allen, 1999) points out, "The hallmark of focus groups is their explicit use of group interaction to produce data and insights that would be less accessible without the interactions found in a group" (p. 31). During my preparations for this study, I noted that SRHB has a history of using multidisciplinary work groups, and so I believed that the care providers who work at the Board's medical clinics were accustomed to working in a focus group setting. I already knew from my initial discussions with care providers that the issues to be discussed in this report were of interest to them. I also felt that a focus group would provide additional reliability to the study by confirming comments made by patients during their interviews, as well as comments made in personal conversations with SRHB medical staff.

SRHB staff working with cancer patients were invited to participate in the focus group session to share their knowledge of their patients' experiences dealing with the Canadian health care system in general and SRHB in particular.

I called on nurses, physician specialists, interpreters, social workers, the medical travel specialist, chemotherapy staff, and the occupational therapist to describe the focus group and to ask for their participation. I then sent written invitation letters explaining the purpose of my study (Appendix A2) with an attached consent form (Appendix B3), agenda, and list of questions to be discussed (Appendix C2). I made follow-up phone calls to encourage participation one week prior to the focus group session.

The two-hour session with eleven participants was held on February 16, 2001 in a SRHB meeting room. Participants represented several Health Board departments, including patient medical travel, medical day care, language services, medical clinics, and physician specialists. Their familiarity with each other allowed for a cooperative atmosphere. I briefly outlined the purpose of my study, and made sure that the participants understood the information I had sent to them. I made the point that while I was interested in discussing patients' experiences with getting through and around the health care system, I preferred that the focus remain on services received from SRHB. I also emphasized the need to focus on what caregivers had been told by their patients and not what the care givers felt their patients needed or wanted--a point that was restated a few times during the session. I described the purpose of audio taping the meeting and tried to keep handwritten notes of my own thoughts and observations. Each participant signed an individual consent form.

As with the one-on-one interviewees, focus group participants were offered the opportunity to review the transcripts of the meeting to ensure that the information accurately reflected what had been discussed.

All of the participants indicated their preference to wait until the study results had been written up. One focus group member volunteered to assist with identifying major themes and establishing recommendations for this report.

Data Analysis

This opportunity to hear patients describe their lives with cancer in the Western Arctic was a powerful experience for me. I came away believing that the participants had a sincere desire to share their thoughts, feelings, and insights in the interest of helping to improve SRHB cancer services.

Prior to analyzing the data, I examined my own methods of interpreting the meanings of what I had been told in interviews and the focus group session, and how that information was connected to the central research question. Following each interview I spent some time reflecting on what I had just heard and recording my thoughts, observations, and feelings in my research journal. I used the time to summarize the key points of each interview, to describe the interview process itself, and to try and understand the participants' emotions and any non-verbal information that could not be captured on audio tape. This proved to be valuable when attempting to make sense of the large amount of data I collected.

Following the lengthy transcription process, I re-read the text numerous times, occasionally listening to the tapes simultaneously to make sure I had not missed any key points.

While reviewing the raw data, I produced a list of five tentative categories that were either discarded or refined down to two major themes, each having sub-themes (all of which will be described in detail in the following chapter). At this time I also began the process of selecting excerpts for presentation in this report.

I was not able to take time immediately following the focus group to reflect on the experience and to record my thoughts in my research journal. When I looked at my notes two days later, I panicked, since they were filled with jumbled and incomplete sentences, doodles, and blank spaces. I then realized that I had actually stopped writing and instead actively listened to what was being said during the focus group session, and wondered if I had been too occupied with taking good notes during the one-on-one interviews. This helped me to become a more attentive listener during the remaining interviews.

After having this insight, I spent the next three hours listening to the tapes of the focus group discussion, reflecting on what had been said, and writing a summary of what I felt to be the essence of their collective voice. Thus, the focus group's comments enriched the themes identified from the patient interviews. I then began the process of placing comments in the categories I had established, and started to identify themes for recommendations.

Trustworthiness

As a researcher, I felt responsible to the participants, organization and community for ensuring study validity and meaningfulness.

According to Fenwick (2000), "Trustworthiness is the extent to which data can be trusted as an authentic representation of the experience of the people being studied" (p.2). The four trustworthiness criteria that I consciously applied throughout the study were credibility, conformability, dependability and transferability.

I felt that credibility was established by the size of the sample - 34 cancer patients residing in the Western Arctic, representative of a culturally and geographically diverse region. At the halfway point I felt that the responses had become somewhat repetitive, and noted common themes in the participants' experiences. I consulted with my sponsor and my advisor about the value of continuing with the interviews; seeing that I was involved in a qualitative study, and felt that I may have collected a sufficient body of data. My sponsor, whose background is in quantitative research, believed that a larger sample size would help in terms of validity. In contrast, my advisor suggested that I screen the remaining participants and attempt to identify four or five participants who did not match the demographics of those already interviewed; I identified three. When I discussed with the program nurses my intention of canceling the remainder of the interviews, they reminded me that the previous interviewees had expressed appreciation and a sense of validation by being invited to take part in the study, and that many considered it a gift to offer me their stories and to volunteer their time. I thus chose to proceed with the remainder of the scheduled interviews, which resulted in a richer pool of data that added to the study's authenticity.

To enhance research validity I used multiple data sources: one-on-one interviews, a focus group discussion, and a literature review.

In addition, five participants reviewed the transcripts of their individual interviews, and three of those same participants, along with two program nurses, one focus group participant, and the Medical Director, reviewed and confirmed the study themes and recommendations I had drafted.

To meet the dependability criteria, I compared my findings with those of similar studies and found them to be comparable. I discussed these with SRHB medical staff, colleagues, and other community health care professionals who specialize in cancer treatment. They supported my conclusions and recommendations, and were not surprised by the findings.

To ensure transferability of this study, I have provided sound data in sufficient detail for readers to generalize within their own contexts. The interpretation I have offered is consistent with the data.

Ethics

In keeping with university and SRHB policies on research involving human subjects, this study was submitted to the Royal Roads University Research Ethics Board and Stanton Regional Health Board Ethics Committee for approval prior to collecting data. Informed consent was obtained from all participants, both individual interviewees and focus group members. Participants were made aware of their freedom to withdraw from the research at any time.

Eliminating all names and other identifying information from the final report protected the privacy of all interview participants; all data was stored in a locked cupboard. All transcripts, tapes, and other raw data will be destroyed following the acceptance of this project by Royal Roads University faculty.

CHAPTER 4 – RESEARCH STUDY RESULTS

STUDY FINDINGS

Think

The next step in the research process was "think" which is the interpretation and explanation phase in Stringers' (1996) cyclical action research process. At this point in the study, the thoughts and experiences of the patients I interviewed, along with the stories these patients shared with their care providers are interpreted and explained. The enormous challenge I faced was to present these stories in a meaningful way. Kirby and McKenna state, "When the data is being described or explained, the voices of the participants need to be given priority. In this way the researcher can provide a forum in which the experiences and thoughts of the participants can be expressed" (1989, p. 156).

As I read and re-read the transcripts and listened to the audiotapes I searched for the meanings in what the patients told me. Beginning with their initial diagnosis of cancer, patients described their experiences with the various health care providers they encountered along the continuum of their care. Overall they felt pleased with the services they had received. They spoke from the heart about the things that worked well for them and the things that did not. Initially I did not see much to analyze in the data. I became concerned that perhaps I had not asked the right questions or was it that I had not listened well enough? Their stories and the obvious sincerity and openness with which they shared these experiences intrigued me into taking a closer look.

Only after re-listening to the audiotapes, reading the transcripts many times over and referring back to my initial notes and research journal did I see two predominant themes begin to emerge. I was then able to analyze these themes separately using a thematic analysis approach (Marshall & Rossman, 1999).

From the patients' perspective there are two main aspects which contribute to effective care at Stanton Regional Health Board Medical Clinics: a well organized, systematic approach to services, and services that are offered within a supportive and caring environment. Regarding a well organized systematic approach, patients spoke of the significance of being able to readily access services in the Western Arctic. They spoke of the importance of the continuity of care within this service. Evident throughout the patients' stories was the value of coordination of services within SRHB Medical Clinics and other SRHB units, between SRHB and their family physicians and health centers in their home communities as well as between SRHB care providers and health care providers in "the south." The second over arching theme was one of health care services which are provided in a supportive and caring environment. This is reflected in the patients' stories of the information they have and of knowing what to expect. It is about having competent and caring care providers. It is how they are treated and the support that they receive.

A Well Organized Approach: Systems that work like a system.

Access to Services: The closer to home the better.

Services at the SRHB Medical Clinics are provided by physician specialists on a consultative basis. Patients require a referral from either their general practitioner or in the case of patients living in the communities, a referral from the general practitioner who provides outreach services to that community or the Registered Nurse in charge. When asked about their experiences with accessing the specialist services at SRHB Medical Clinics, interview participants (23/34) commented that they had relatively quick and easy access to services. I will illustrate this and subsequent points with direct comments from participants:

> One minute I am in my family doctors office and the next week I have been seen by the specialist and had a biopsy done. It all seemed to happen so quickly. I was sent south within three weeks for further treatments.

> One morning when I was in the shower, I found a huge lump in my breast. I called my family doctor but he wasn't in clinic that day. His nurse tracked him down and he told me to meet him in the emergency department. He did an ultrasound right away and then called the specialist. I went right over. It was that fast. I was thankful I did not have to wait.

While the wait to get an appointment with the specialist was not considered to be lengthy by some, other patients (5/34) spoke of the anguish of waiting for the day of their appointment to arrive.

> Originally my appointment was six weeks away. After a few days I was so worried…I knew I had cancer…I was sure I was going to die…I could not sleep or eat. I got myself so worked up. After about a week I phoned the nurse at the specialist's office. She said she would talk to the specialist and put me on a cancellation list. To my relief I got an appointment a few days later.

> When I finally got to see the specialist after three weeks my worst fears were confirmed. They were pretty sure that I had cancer. A biopsy and a few more days wait. It seemed like eternity. When it was confirmed that I did have cancer I wondered if I had been seen sooner would it have been detected sooner, would that have made a difference to my prognosis?

When care providers were asked what patients have told them regarding access to services at SRHB Medical Clinics they shared the following:

> Most patients tell me they didn't have any problems getting an appointment seeing the specialist. They know the doctors are busy but when it is for something important like maybe cancer and the patients are scared, they try not to make them wait.

> It is not something I have heard patients complain about. If anything, patients tell me how quickly things happened.

Specialists from the SRHB Medical Clinics also provide outreach clinic services to the communities of the Western Arctic. Patients appreciate care provided in the community allowing them to remain with family and not having to take time away from their work.

> Sometimes I see the Dr. for check up when he visits the nursing station and I like that better than having to come here [Yellowknife]. Better for my kids, I don't need to find someone to look after them.

> I operate my own business so having to take time off even a day to come to Yellowknife means loss of income for me and my family. It has been better this past few years when I can see Dr.__ when he is in Hay River.

In some of the larger centers such as Fort Smith, Hay River and Inuvik the facilities are equipped to allow the specialists to perform certain additional tests and procedures that the patients may otherwise have had to travel to SRHB to have performed. Patients are appreciative of this service.

> I don't have to come back to Yellowknife as often now 'cause I can see the doctor [specialist] when he comes to Hay River. Last time they did my scope in Hay River and saved me a trip here. Better for me. I only have to come to Yellowknife if I need tests they can't do at the hospital there, or if I have to go to Edmonton to see the oncologist there.

> I had my last scope at the hospital at home in Inuvik when Dr.__ was there, so that's good. The only reason I am seeing him here now [in Yellowknife] is because I am on business and missed my appointment last month when he was in Inuvik. The staff here keeps a pretty close eye to make sure we don't forget our follow up appointments.

The sentiments of these patients who prefer to be seen in their home communities were reflected throughout the focus group discussions. One care provider stated:

> When I am in the communities, patients tell me they prefer to have treatments as close to home as possible. When I explain to them why some services can't be provided in health centers or smaller hospitals as opposed to here [SRHB] or even Edmonton for that matter, they say they understand.

A challenge cancer patients face living in the Western Arctic is that many of them live outside of Yellowknife in more isolated communities and must travel to access necessary medical services. In spite of being in a remote and isolated location, patients say they have very good access to services.

One participant, who lives in particularly isolated circumstances, shared his story of initially accessing services at SRHB Medical Clinics to have his cancer diagnosed and treated.

> I got into trouble...this was late April when we are completely cut off at that time of year. It was break up on the river so you can't travel by water and it's too wet in the muskeg to go by skidoo.

> So that's one of the two times a year we are stranded for about 3-4 weeks. Living on the river the only way to get out at that time of the year was by helicopter....I knew I was in serious trouble....I was in great pain and it was almost pure blood coming out at that point. We got on the radiophone. There was only about an hour of daylight left. It was kind of dicey...I radioed the nursing station and when they heard my symptoms they sent a chopper with a nurse to pick me up. The Doctor wasn't in the community but the nurse in charge was excellent. That was when I was introduced to catheters and what a wonderful relief. I was kept over night in the community... The next morning I was sent to Yellowknife to see the specialist. I would have gone on a scheduled airline except there was another medical emergency so we were both sent on a charter. Bad weather... and we wound up having to take quite a long route in a single engine plane. Three to four hours to get here. So considering where I was, the location you know, I was here in a good facility with specialists care within less than 24 hours. We have an excellent system.

Other patients speak of the improvements in the level of scheduled air services into the smaller and more isolated communities:

> You know before...maybe twenty years ago...we had planes only once a week and lots of times the plane couldn't land because of weather and if it wasn't weather it was mechanical. Now days we have planes every day of the week and two airlines...better airport...new one built a few years ago. Always a good thing though...the nurse at the health center is always there and if someone is real sick they get a plane to come in right away to take the person out and not wait.

One patient tells of his journey to get to his appointment with the specialist:

> It was a long day to get here, this time it took three stops on the plane, although they have some direct flights straight here...I just never seem to get them.

He further recognizes the cost incurred are covered under his health care plan:

> And our travel and accommodations are covered by our health plan; we're fortunate in that respect.

One patient compares access to services in the Western Arctic to experiences of his family who live in northern Ontario:

> I live 600km by air north of here and I can be here in within a few hours. That's better access than my parents have in northern Ontario...my dad had to go 8 hours by ambulance to Toronto...which he had to pay part of the costs. Here our healthcare plan will fly us to the nearest location for necessary medical services...so it is actually quicker and better.

This is consistent with the literature by Ng et al. (1999) who presented evidence suggesting that the cost of receiving health care in remote areas is not a barrier to access even when transportation between rural towns and urban areas is a factor.

What the care providers reported mirrored what the patients shared regarding their preferences for services, which are provided closer to home:

> We hear from patients that they would like to be seen first in their home community and if the services are not available, most patients from the communities would prefer to come to Yellowknife rather than go to Edmonton....especially aboriginal people because for some of them it is their first time out of the communities.

These findings are consistent with the literature review. The Western Arctic is challenged by geography, climate, isolation, the availability of local resources, and distance to care centers. Watanabe and Casebeer (2000) have recently described some of these unique issues that residents face living in rural and remote communities. They further argue that these issues must be examined and analyzed through the lenses of rural, isolated and northern for their impact may be magnified or differ in these communities. Lessard (1994a) promotes personalized service delivery that would allow patients to remain in their home communities for care. According to the Final Report of the First Ministers Forum on Health and Social Services (GNWT, 2000c) residents of the Western Arctic have strong expectations of quick access to health care services provided as close to home as possible when needed. This message has been reinforced once again through the stories of the participants in this study.

Continuity of Care: Another new face, another person to tell my story to.

For many patients the ability to develop a close and trusting relationship with their healthcare providers is important. This is accomplished over time and with consistent health care providers. Several patients shared a range of experiences.

Patients expressed appreciation for the continuity of care providers:

> It is nice they recognize me, know my name, remember all my tests and procedures I have had done. I know __ [nurse] will remember to call me for my next check up or if there is anything else I should know...

> You know, you develop a relationship with your nurse. It's comfortable to be able to call, say what you need without having to go into great detail. They go the extra mile and try to make things as easy as they can...like when I had to go to Edmonton for tests and was supposed to stay six days. She [the nurse] called down there and they got things changed around so that I only had to stay three days...and still get everything done. People like that make the system work *for* the patient [emphasis added].

One patient expressed appreciation for the interdisciplinary coordination of his/her care:

> I had to have an operation for something else so my doctor and the nurse worked to coordinate the procedures and I had it done at the same time as my cancer surgery. So only one anesthetic, one hospital admission. I appreciated all the coordination required. It made it much better for me, less stressful.

Some patients spoke of having to tell their story several times over to various healthcare providers in the SRHB Medical Clinics, or of not knowing which care provider they should be seeing or not having all the information available:

> You know, I have had four nurses since I have been coming to this clinic and two…no…three doctors taking care of me since I started to come here…and that's not counting the doctors who have been here when my doctor is away.

> I got to the point of not knowing who I should see for what problem. If it is my hip pain I go to this specialist, if it's my menopause I go to Dr__. if it is a prescription refill for routine stuff it is my family doctor. I have been running back and forth between my family doctor and three or four other doctors.

> Lots of times all my tests and reports aren't on my chart so I have to explain even more to the new person where I have been and what I have had done. Don't get me wrong, they have each been good, in their own way, very good skills. But I just get tired of repeating myself.

Some patients indicated they would prefer to continue their relationship with the same healthcare provider and will wait, if they can, until their regular physician is available to discuss issues and concerns:

> If it's not that important I will wait until my regular doctor is back so I don't have to tell everything to someone new again…and for what?

> Don't have the patience for it anymore. Not like the old days when you had the same doctor for most of your whole life.

> This guy was very nice, good doctor but I find, if it's a new person I just don't say much. It is easier to wait until my regular doctor is back. Today I had to explain a bit more because he didn't know I had been in this experimental drug program. Guess my reports haven't come back from Edmonton yet.

These comments by patients were reflected in what they shared with their care providers:

> The real common thing patient's mention is the continuity. They like coming back and seeing familiar faces and speaking to the same person.

> One elder told me he liked that his doctor understands him…he knows him for a long time now and even though he's not supposed to…he chews snuff …his doctor… he teases him and at the same time is serious…wants him to stop…but he [the doctor] understands that it is a small thing...he says it's okay.

These findings are also consistent with the literature. The patients interviewed value continuity of their care providers. As evidenced throughout the patient stories, continuity of care is important especially when all the relevant information may be on the patient record. As well, a continuous relationship is thought to promote trust, which is a key to the care provider – patient relationship.

Sherer et al. (1993) affirm that the concept of care continuity is important and that the promotion of trust is a core part of any relationship between care provider and patient. Further, the continuity of care provider encourages patients to raise issues, to confide at a deeper level and ask questions that might otherwise be kept inside. Guthrie (2000) found that patient satisfaction is strongly associated with seeing the same doctor. He also links greater patient satisfaction to being treated by physicians whose practices are smaller, who do not have residents, interns or students and those who maintain patient follow up lists.

Co-ordination of Care: Talk to each other. Be a team.

Guthrie (2000) links the importance of continuity with the coordination of care. He suggests continuity of care can be enhanced by the appropriate organizational guidelines, the use of electronic records and information system.

Patient at SRHB Medical Clinics indicate they prefer a system in which health care providers work together effectively. They want care providers to know and understand their unique needs and circumstances. Patients interface with numerous health care providers – specialists, general practitioners, residents, medical students, nurses, therapists, interpreters, medical travel personnel, and have at best, a vague understanding of a system which is organized to accommodate provider schedules and routines. The resulting confusion is not insubstantial.

Some patients expressed frustration with the number of care providers involved in their care and the apparent disconnect between the various care provider groups. This includes services between SRHB Medical Clinics and other SRHB departments.

> I find I have to repeat much of the same information over and over again…to the hospital admitting desk, the receptionist in the clinic, the nurse, the doctor…then I had to go up to the day care unit and tell the staff there many of the same things…and some of them pretty basic…then I see the anesthetist and she asks me the same questions the nurse and two other doctors before her asked.

Another patient adds:

> I know they want to make sure I am the right patient and they have the right information but it seems as if no one takes the time to read the papers and information I have from the specialist who just saw me downstairs. It is as if everyone has to hear the information themselves for good measure.

It is difficult for patients to sort out all of their appointments and keep track of who they have told their story to, especially as appointments are often in several different locations:

> I have had so many people poke and prod me I cannot keep it straight anymore. Last week when I got back from the oncologist in Edmonton I had an appointment with my regular doctor [family physician] and she had a medical student that spent a lot of time with me…going into detail about my medical history. Then today with the specialist and there is a third year resident…or was that a medical student…with him. That was a bit much for me.

> Showing up at the wrong place was frustrating. No one knew where I was supposed to be going.
>
> My paper just said to come to the hospital at 9:00am to see Dr. __ for an x-ray. I find out that my appointment with Dr __ is in another building at 9:00am, my x-ray is booked for 2:00pm, and I am supposed to leave on the plane to go home at 2:30pm. Not sure why this information is not getting passed on.

Patients appreciate being assisted with directions:

> When my appointment with the doctor [specialist] was over the nurse helped me to go to the other places. She took me upstairs with my papers and introduced me to that other nurse.
>
> I had a hard time finding where my appointment was supposed to be...my card said the Stanton Hospital so the boarding home drove me here. The lady at the front desk did not know where she was supposed to send me. She phoned everywhere and I waited. Then it turns out I missed my test...I was too late...the nurse helped me to get a new time...no body told me what time was test.

Comments from care providers affirmed the patient's comments.

> Patients often ask me to take them to the other departments, as they are confused about where to go and worried they will not find it.

> I don't mind helping patient to find their way but often I am in the middle of running a busy clinic, but there is no one else to help so you just do it for the patient.

> Patients have suggested we have a greeter like they do at Wal-Mart. That would be a good job for me when I am not quite ready to retire. What about using volunteers?

Patients are aware that pertinent information such as lab work, x-rays and consultation reports are sometimes not on their charts at the SRHB Medical Clinics prior to their scheduled appointment.

> I have blood work done regularly and things work well but sometimes my results are not back by the time I go for my doctors appointment and the nurse has to phone around to get the results for the doctor.

> I had an IVP done last month but when I was here today [SRHB Medical Clinics] for my follow up, the nurse had to look for the reports and it was a bit of a delay.

> The specialist wasn't aware that I had had several tests done by my family doctor. His nurse spent a lot of time trying to find the information.

In 1999-2000 SRHB Medical Clinics had an approximate "no show" rate of 23%. A patient is considered to be a no show if they have not called to cancel or reschedule their appointments. If this time can not be rescheduled it contributes to the inefficient use of the specialists time. It also consumes staff time when they have to reschedule appointments and procedures.

One patient recognized the time spent by a health care provider to coordinate his appointments to ensure he would be able to keep them and make the best use of the specialist's time.

> I don't like having to come to town at that time of year. So the nurse said okay…when is a good time that you will come? The nurse tries hard to fit me in cause it was important to get my cancer checked up. Before, I should have paid more attention to wasting the doctor's time when I didn't come. Would have been better for me too. Get the cancer out sooner.

A member of the focus group reinforced this comment.

> We have our work cut out for us trying to make sure patients don't fall through the cracks. When I talked to this one patient about having to reschedule his OR for the third time…I think he could sense my frustration. When I explained the number of cancer patients we have waiting to have operations, he told me he hadn't realized all the work it takes to coordinate all these things, and by not showing up it is time other cancer patients who are waiting as well could have been booked in.

When patients from other communities are at SRHB Medical Clinics and a need for further testing or consultations is identified, every effort is made to coordinate the service while the patient is still in Yellowknife.

This reduces the need for additional travel, potential time loss from work and family as well as the reducing the anxiety of the patients. This patient shared his appreciation.

> A few years ago while I was in Yellowknife on a workshop I booked my annual check-up…not because I was health conscious but because it is a job requirement. As part of the routine exam my doctor found a lump. Rather than making me go back to Cambridge Bay and come back to see the surgeon, they got me an appointment while I was here. I am glad they did fit me and I did not have to go back home and come back. I would have worried about it longer plus miss more work not to mention the cost to the healthcare system to bring me back. When the system works like a system, it works well.

Patients are confused at times by arrangements made between SRHB Medical Clinics, the family physicians and the community health centers. Although most patients (31/34) could articulate the reason for seeing the specialist at this particular time some patients are still confused about why they have been booked for their appointment.

> Not quite sure why I was sent…for my cancer check? The nurse [in the nursing station] just told me to come. I went to the front desk here [at the hospital] and they sent me to the emergency department and I waited there and then they sent me to the medical clinic here only to find I had to go to the other medical clinic down the hill. They didn't know why the nurse told me to come now.

> My appointment is supposed to be when the doctor is in Cambridge Bay at the end of the month. It's okay it's done now.

One patient knew why he was referred to the specialist but the SRHB Medical Clinic staff was not aware he had been told to come to see the specialist.

> The first time I came here to see the specialist...my doctor at home told me he spoke directly to the specialist and he told me I have this appointment. When I got here nobody knew I was supposed to be here. They couldn't find my name or any information and the doctor I was supposed to see wasn't even here. Lucky the other specialist was here covering for him. Everybody was good, really tried to sort it all out. Things worked out in the end but it made me wonder...don't people talk to one another? Shouldn't they know these things?

Several care providers indicated they had heard similar stories from the patients.

> Patients often tell us that they are really not quite sure why they are here. They just come because they are told to come by the health center or their doctor.

> Yes, it happens all the time. The people just think okay, the nurse says I need to go so they just get on the plane and go. It is not in their nature to question why or if they should or shouldn't be going to the doctor.

> Patients often tell us that they saw the Dr. on call in emerg and he told them just to come to the clinic [SRHB Medical Clinic] first thing the next morning.

And from one care provider's perspective:

> Sometimes I don't know why they [the patients] are here...I do not always get all the information I need...you can read the information that has been sent with the patient and then you ask the patient's view of why they are here, and the patient tells me they do not know or it is for something totally unrelated to the referral. The disconnect between the two is amazing. Then you really have two jobs. You have to deal with why they were referred and most importantly what is the patients real concern?

Patients spoke at length of the coordination of services between SRHB Medical Clinics, and health care facilities in the "south." Patients are surprised SRHB Medical Clinics and other SRHB units may not always be aware of appointments they may have scheduled in southern facilities such as the Cross Cancer Institute (CCI) in Edmonton or have their information following their appointments. This patient took personal responsibility for her record management.

> I found I had to be vigilant in updating my family doctor here in Yellowknife and my specialist about each visit I made to the Cross. I found often they [family physicians and specialists] did not get copies of test or copies of the oncologists' letters so I started keeping copies of all my records. Now I bring them with me to all my appointments.

These patient perspectives were reflected in the focus group discussions.

> The Cross is generally very good about reporting back on initial assessments. For any other further follow up...if they have asked patients to go back [to the Cross] we don't necessarily hear about it. We may not be aware of it until the patient calls for a travel warrant to say they have to go.

> Patients say they are surprised that we [SRHB Medical Clinics] do not know what they had done in Edmonton...Most of the time the Cross is very good ..they have improved over the last few years. Sometimes I have to phone them [the Cross] after the patient phones to get copies of tests or consults or whatever it is they had done.

Western Arctic patients who live outside of Yellowknife and must travel by air to access services spoke of the time it takes some of them to get to Edmonton for a relatively short appointment with a healthcare provider.

> I had to come to Yellowknife, overnight here then go to Edmonton for a CT scan and didn't even see another doctor. Wasn't sure why I was having the CT scan there when we can do them here [SRHB] and the film sent to the Dr in Edmonton. I had to be away from work and home for four days to be seen for less than one hour....just hi how are you...how are things going? Good. See you in six months.

> I think my Dr in Edmonton thinks there are no services available outside of Edmonton.

Care providers shared that they had heard similar stories from their patients.

> Patients often expressed frustration about traveling to Edmonton for services they felt could be provided at SRHB. Especially the five-minute ones for just a chat.

> I had a patient come back and tell me that exact scenario. She thought maybe we shouldn't pay the doctors bill because she saw him for about 60 seconds. She raised that concern. She didn't think we should have to pay the bill for that.

Some patients have begun to request to be seen in Yellowknife by the specialist rather than going for follow up in Edmonton.

> I had been getting check ups in Edmonton for my cancer for about two years or so and the last time when I was supposed to be just going for a check up to Edmonton, I asked if I could be seen by my doctor in Yellowknife rather than go all the way back to Edmonton for a five minute appointment. The nurse here phoned and arranged it so I could be seen here by the specialist and it was arranged. It was great.

> My friend sees her cancer doctor here [SRHB Medical Clinics] but she's [oncologist] not a doctor for my kind of cancer. We should get cancer doctors here for breast cancer so I don't have to go to Edmonton as much.

One care provider said:

> More and more patients are asking to be seen here [SRHB] rather than go all the way to Edmonton. Whenever possible now...if we know about it we contact the Cross, and if we can we provide the service here we rebooked them in Yellowknife. We send test results back and forth [to the Cross] all the time.

When asked what we could do at SRHB Medical Clinics, to improve services several patients interviewed suggested that regular Oncology services from Edmonton should be provided in Yellowknife. They see this as being particularly beneficial to replace the times when they have had to go to Edmonton for brief follow up visits and a short discussion with the oncologist.

> Bet you a fair amount of us patients go to the Cross for follow up that really don't need to go. There has to be enough of us going south that would make it worth while for them...the government... to pay for Dr.__ or someone [Oncologist] to come to Yellowknife every few months.

> For the number of trips I have made to Edmonton and the money it cost the system, just to see the doctor [oncologist] for a few minutes you could have paid his way up here every month.

Some patients recognize certain limitations in providing itinerant Oncology services at SRHB:

> I would love to have my oncologist do clinics in Yellowknife but I know visits by an oncologist to Yellowknife won't mean that people will stop going ...some patients will still have to go to Edmonton...there is only so much that can be done here. I think the oncologists are specialized and see only certain types of patients. I know my oncologist specializes in my kind of tumor...so what happens when an oncologist comes who doesn't deal with my kind of tumor?

As well patients believe this would provide the opportunity for improving the understanding health care providers in the "south" would have of the services available in the north.

> I don't think my Dr. in Edmonton [oncologist] knows just how far it is for me to come for a ten-minute appointment, to ask me how I am, pat me on the knee and say everything looks good, come back in three months. Why don't we have them come here like we do with the other specialists? Once he sees what is here I think it would be better for cancer patients.

> If we have the Cross come up here to do clinics they will be able to go back and tell their colleagues and other staff there... just how much of the services are actually available here [SRHB] and can be offered in Yellowknife.

Some patients recognize the added benefits having oncology services at SRHB:

> It would be good if the oncologist came. There could be educational sessions for the general public, staff and patients.

Another patient would prefer to continue to travel to receive services from an organization that specializes in cancer treatment:

> I like being able to go to a place like the Cross and know that they are the experts in cancer care. They have all the resources there. We are fortunate here considering where we live...and the people who live outside of Yellowknife. The reality is we will never be large enough to develop programs to that level with the people and the limited resources we do have.

When asked what SRHB Medical Clinics could do to improve the services she further adds:

> What would help is to better co-ordinate the services that are provided between Stanton and the Cross.

Research suggests that the lack of a coordinated approach impacts patient outcomes and increases the likelihood that patients will have adverse experiences with receiving necessary medical care (Ford & Fottler, 2000; Guthrie, 2000). A co-coordinated approach to cancer care services is consistent with the findings in the literature. Through patient surveys, researchers at the Piker Institute have identified the co-ordination and integration of patient care as one of the eight areas of patient care in the United States which requires immediate reform.

Paying attention to the patients' perspective has become increasingly important (Gerteis et.al, 1993). The Supportive Care Working Group for the Canadian Strategy for Cancer Control has addressed the shortfalls in the delivery of cancer care in the context of important principles of care. The document states "Co-ordinated care for information and interventions among all stakeholders involved in the process of supportive care of cancer patients is needed to work towards the same objectives and consistently implement strategies" (Health Canada, 2001a, Appendix 1, p.31).

A Supportive and Caring Environment.

Patients want services to be provided in a supportive and caring environment. To the patients SRHB Medical Clinics, a supportive and caring environment includes having information about their cancer. Patients want to know what to expect. They want the information in order to understand what is happening and to be able to make informed decisions regarding their care. They want this information provided by caring, compassionate and knowledgeable care providers.

Although the patients I spoke with were diagnosed with different types of cancers, the one thing most patients (33/34) had in common was the fear they felt when they were told of their diagnosis. Most of them said all they heard was the word cancer. Most said they remembered very little of what they were told immediately after that.

> My first thought was I am going to die. I was so scared I began to shake inside and out. I knew I would be dead before Christmas. Then I thought of my children and began to cry.

> You don't want to hear the word cancer so you just block it out.

> I felt numb...a sense of dread. It was like I was hit by a ton of bricks...I think I stopped listening...then I thought...maybe it's a mistake, there is a mix up, repeat the tests. I'm not sure what the doctor said after that.

Only one patient stated:

> I didn't think nothing, didn't feel nothing. They told me I had cancer ...I wasn't scared...I said okay...cut it out. It was my wife that was scared.

Information Needs: So what happens to me now?

Patients are frightened, not knowing what is going to happen next. Most of them shared that initially they had limited knowledge of hospitals and the various tests and procedures they would undergo to obtain a diagnosis.

> I came for a check up for pneumonia and maybe x-rays... Never been in the hospital before. Doctor told me I had cancer...three days later I had a operation in Edmonton...things stuck in me everywhere...a big one [tube] in here [chest] to drain the stuff off inside...in my arm...one so I can pee...first time in the hospital...phew...never knew that could happen to me.

> Thought they would just check me up…not do things…the doctor he stuck a big needle in my bone and took out my blood and stuff to check…Still sore here. [Left hip]

They also had limited knowledge of the various medical specialties that are involved in their care:

> Never knew there are so many kinds of doctors…so many to just take care of one kind a cancer.

> Too many people checkin' me.

Care providers reaffirmed that for many cancer patients this was a new and frightening experience.

> For many patients especially from the communities they tell us there is too much coming at them. Everything from the town is bigger, lots more cars, they can't find where to go in the hospital, people poking and prodding them. Then they are told they have cancer that scares the living daylights out of them.

> Over the years I have interpreted for many cancer patients who are scared when they hear the word cancer. Families lots of times don't want us to use the word just say to that person that they are sick and what the doctors going to do. But don't say cancer.

When asked, a surprisingly high number of patients (28/34) stated that they felt they had received enough information about their cancer care and treatment. SRHB cancer patients need different types of information at different times. This is well supported with the findings in the literature review. (Ashbury et al.1998; Fitch 2000; Whelan et al.1997).

SRHB Medical Clinic patients identified that information about their cancer came primarily through conversations and dialogue with doctors and nurses and other health care providers. Care providers where supportive and caring in providing information.

> When I look back I got most of the information I needed as I went along...from my family doctor, my surgeon, the nurses, my physiotherapist.
>
> The doctor was good to explain everything he was doing. I was given instruction sheets and the nurse went over things in the clinic. Then when I went to the floor before my operation the nurses there went over things again. All along the way I had the opportunity to ask questions and get answers. They have always been very prompt at returning my phone calls.

As well some patients stated they relied on other cancer patients who have had similar experiences for information as well as support. This is consistent with the literature review. Buckman (1995) affirms that at the deepest level the only people, who understand what cancer is like, are others that live with cancer.

> There's another guy in town [small community] with cancer. A different kind of cancer...he's had it for a couple of years so when I got mine he came to see me ...and told me some things. It was good to talk to someone who's been through the same things. Now I can do the same for others.

> After I was diagnosed __ [cancer patient] came to my house and brought some information and a videotape for me to watch. It was good information. I wasn't quite ready for it at the time but it was there when I was. She was a stranger to me yet she knew exactly what I was going through.

Patients used a combination of books, pamphlets and other written material and a few used the internet as a resource. A few patients accessed written information and videos through local support groups.

> I read all the information that I could get my hand on. I was determined I would be strong for my family. I put on a brave front and kept busy becoming well informed.

> There are a few very well respected sites on the internet. I could give you a list for other patients.

Many patients indicated that they preferred not to discuss their cancer with anyone other than their care provider and their family and the patients indicated their wishes were respected.

> I am not interested in support groups, talking about my cancer or reading up on it. I get the information I need when I need it from my doctor or nurse. It bothers my wife to talk about it.

> I was offered support groups and visits from cancer people. I appreciate their offer but I have my family. I was told the offer stands, if I need it. They have respected my wishes.

> In my culture people do not talk about cancer or use the word. They don't like to talk about wills or things like that. People think if you talk about it, you could get it.

As the researcher I recognize that what constitutes 'enough' information will vary with each individual patient depending on factors such as the availability of information, patient's readiness to receive and process information, cultural norms, education, and socio-economic status. I noted that although the majority of patients (28/34) stated they had received what they interpreted as enough information, when they spoke of their actual procedure or treatments or a process in their care, many patients (19/34) identified information they felt they would have benefited from having. Based on the variability in responses and the likelihood that they will be influenced by circumstances, it is difficult, if not imprudent, to determine what the 'right' amount of information is in any generalized sense.

Patients identified a desire for more information about their treatment and intervention options. Many patients needed someone to walk them through the system.

> There were really no discussions about what my treatment options were. I went ahead and had the surgery. It was probably the best option but the fact was I was presented with a course of action, not what the options were and why this one is the best choice.

> The lymphedema I was not really prepared for. What I didn't get was the little things for after...things to help deal with my swollen arm, how to get my sweater on, what helps for radiation burns. Information for things like that would help.

> At first I was given the course of action we would take to deal with my cancer. So you move along doing what needs to be done. I think I was still in shock and at the time felt I was well informed. As I started to talk to others who had been through this I thought...hmmm...that was never discussed with me. I wonder why? So then I read more, asked more questions...got more information on my own. I wonder about people who, for whatever reason, don't get to where they ask questions and advocate for their own health.

They also required more information about hospital processes and services.

> I didn't know I would have to wait so long in each place. I didn't expect to be here all day. You sure have to march to the tune of everyone else's drum.

> I didn't know that could be done here [SRHB]. Why have I been going to Edmonton?

> The last time I was in the hospital the nurse told me it was okay to burn the sweet grass. It's important to my healing. All the times before I never knew this was okay.

Some patients want more information about their healthcare benefits:

> I think somebody should sit down and explain your benefits to you at a time like this and how your forms should be filled out ...I did not know what I had to pay for and it stressed me.

> I thought healthcare was free in the NWT. I know things happened fast but it was a shock when I got the bill for the co-payment of $250.00. Then if __ hadn't told me I wouldn't have known I could get it back through my employer.

They also required information on support groups and services:

> In retrospect it would have been good to have written information about the support groups available and be able to call them when I was ready. I think I was told at the time of my diagnosis but the information did not sink in.

> Initially I was shocked...by the diagnosis so I don't really think I could handle much more but maybe just to give the phone numbers and make sure I knew who I could call [a support person] when I was ready...would have been helpful.

Care providers offered the following insights:

> Often patients are in shock when they first find out they have cancer, that they do not hear some of the information or the details we give them that they need to know at the time. I have had patients come back and say they were never told something. I wonder if it is they were not ready or capable of taking in any more information.
>
> This is why we try to bring the patient back shortly after they have been given their diagnosis, to reinforce what has been said, offer the information once again with perhaps a bit more detail, presenting it in a different manner, trying to be sensitive to individual styles of taking in and processing information.

One care provider provides the following feedback. Although it was not mentioned by any of the patients in the interviews, the information is significant:

> Some of our patients show us some of the pamphlets and written information that they have received. The patients find some of the terms we take for granted as common still too complicated. The pictures are very helpful but the written sometime is too medical, needs to be in plain language.

Another care provider reinforced this.

> Yes, lots of times patients tell us they are glad we can do medical interpretation for them so they can understand better.

These findings are consistent with the literature on the information needs of cancer patients. Research has shown that cancer patients information needs may vary depending on what stage they are at in their cancer (Ashbury et al., 1998; Canadian Cancer Society, 1992; & Fitch 2000). Further research, which focuses on the information needs of cancer patients at the various stages of their cancer, is required

This will be beneficial in developing a better understanding of the specific information needs and therefore assist in the planning of supportive care services to best meet their needs (Whelan et al., 1997).

Skilled and Competent Care Providers

Research has shown that patient comfort levels as well as the level of satisfaction with the health care services they receive increases when patients trust the skills and abilities of their care providers (Gerteis et al.,1993). SRHB Medical Clinic cancer patients want to feel confident that their care providers are capable and knowledgeable. One patient shares an experience in which he felt a particular care provider demonstrated these qualities:

> You don't get sent to a specialist for nothing. I was impressed with how thorough my exam was, the time he spent to explain things to me...he called my wife in...drew pictures of where the tumor was, showed us on the scan where it was pressing and why it had to be dealt with immediately. He was calm and no nonsense but [he] left no doubt in my mind this was serious business. I sense he knew what he was talking about...and it put me at ease.

This was reinforced when he added:

> A few days before I was discharged from Edmonton my surgeon there told me I was lucky to have had this dealt with when I did. That reinforced my initial impression of Dr__ It was also good to know I was coming back to a capable doctor. I was lucky to have him.

An elder Aboriginal women spoke of the trust and confidence she has developed after the care providers and family spent time explaining the need for her care.

> At first I didn't want to get the operation. I was scared I said no...not signing the papers...The doctor here [SRHB] told me I had a big tumor. I was so scared. He wanted me to have the operation but I didn't want to sign the papers...He told me if it didn't get cut out it would get bigger and I could get sicker. He talked to my husband and my kids. They want me to have the operation. They said just try...my sister she came and she said he [the surgeon] is her doctor and he is good. Nurses told me too. So I said okay. I'll try. Now it's good...after the operation...no more sick. My doctor is good medicine man.

Patients want information and services to be provided by caring and compassionate care providers. A few kind words go a long way towards creating positive relationships between patients and care providers.

> She [nurse] always takes an interest in me and asks how I am doing...it doesn't matter if it is on the street or in the clinic...and I know she is sincere.

> Sometimes I think the fact that I have cancer is difficult for my doctor. It was difficult for her to give me the bad news. She seems to genuinely care. Some how that makes her a better care provider...at least to me.

One patient stated:

> I just expect my doctor to know what he is talking about. That's why he went to medical school so I leave the medical stuff to him. What's important is that he and I get along. He is very professional...very dry sense of humor. We click.

Unfortunately, this is not always the experience for patients. Some patients feel like they have not been given enough time to ask questions, or not given the full attention they felt they needed.

> Sometimes I feel like I am a bother when I ask questions. It is as if I am questioning their [healthcare providers] authority or knowledge. But all I want is clarification...I want to understand...after all it is my life.

> I think the staff is too busy at times. My appointments seem so rushed. Everyone seems preoccupied. That makes me feel tense. I go away feeling frustrated.

> Staff are excellent at the jobs, especially the physical part doing procedures and things, but I think emotionally for the patient staff need in-services to help understand where we are coming from.

Care providers do not always demonstrate an understanding and sensitivity towards cancer patients.

> I have had comments made to me by staff here [SRHB] which made me believe that they [healthcare providers] think I am going to die. In all the visits I have made to the Cross, my oncologist and his staff have *never* talked to me that way. No one has the right to destroy my hope...and that's what they did here.

A few patients shared their experiences with being given conflicting information:

> I saw a different oncologist at the Cross one time because my regular oncologist was swamped with emergencies. This other oncologist examined me and gave me a very good examination...when it was finished she said "So we'll see you back in three months." When I explained to her where I live and sort of tried to explained that it's not Yellowknife routine, and my family doctor was under the impression that I could be discharged [from every 3 month follow up at the Cross] after that appointment...It was the end of the day...I don't think she knew my history or anything. She just blurted out "No, you can't. You have to come back every three months. Do you *realize* [emphasis added] what you have and the high risk you're in?" My own family doctor had brought up that everybody is at risk but said I was still a low risk person. It was a lot to take...a big appointment and home on the plane in the same day then when I go home...it hit me what she [the oncologist] had told me.

Another patient states:

> The Cross told me I should still have a follow up appointment there [Edmonton] every three months. They want me to continue going to Edmonton. My doctor [specialist] here [SRHB Medical Clinics] feels that I should be able to be followed up here. I am confused…the Cross may be a bit conservative yet. I trust my doctor [specialist] here.

Care providers reiterated these experiences patients shared with them.

> Patients tell me they feel caught. They just want to know that they are getting the best treatments you know and they come with various levels of understanding and knowledge about their cancers.

> The link to the Cross is very important because they are an information resource. Patients tell me it is an important part of having faith in their system. As __ mentioned, most people just want to know that they are getting the best available care.

These findings concur with the literature. Oliver and Wilson (as cited in Lessard, 1994b) indicate that patients acknowledge they are limited in their ability to judge the competency of their care provider. If anything, patients may decide on care giver competency based on whether or not the caregiver has met what the patients see as their needs. Some patients assess the skills and abilities of their care providers based on the level of self-confidence a care provider exudes.

Respect Me as an Individual.

Regardless of their prognosis, or the stage of their cancer most of the patients expressed, in one way or another, the significance of being treated the way they, as individuals wished to be treated.

Some patients referred to it as wanting to be treated "normally", not wanting to be treated any differently than they were before they received a diagnosis of cancer.

> Treat me normally, treat me with respect, empathy and compassion like any other human being but please, do not treat me differently because I have cancer.

One patient tells of her wishes being respected and how it made her feel in control.

> I chose not to have any further treatment. Initially I get the feeling it is not what some people here [care providers] thought I should be doing. My doctor could sense that I was feeling torn. He spent time with me, provided all the rationale for his thinking...we had a very good talk. In the end I felt that the decision was truly mine. He honored my decision and has been a wonderful support. There is mutual respect.

When patients were asked what was important to them when they received health care services their stories reflected a wish to have their personal values, beliefs and traditions recognized and accepted.

Through the interview process it was clear to me that patients are appreciative of being accepted by health care professionals at SRHB as individuals regardless of their individual values and beliefs.

> I am of __ descent but I consider myself Canadian. When I come here to see the doctor, I am treated with the same respect as others and there is no difference made. They accept me for who I am.

> I told my doctor [SRBH Medical Clinics] let me have my medicines the medicine man give me. Makes me strong. He [SRHB specialist] said okay…it's good for me he said okay.

> Having cancer is a stress and makes some people treat you different. I lead an alternative life style…have lived a lot of places…it has not been an issue for my doctor and the nurse here [SRHB] or anyone else…people here do not judge. Good thing …don't need that on top of the cancer…

Of the total number of patients interviewed in this study 19 of the 34 were Dene, Metis or Inuit. As the researcher I wondered how much the structure of the interview process and the fact that I am a healthcare professional in a system using a western medical model, would influence the interview experience for the patients. The Aboriginal patients I did interview seemed genuinely willing to share their experience with me and pleased to have the opportunity to participate. I found in the end my over all sense was that they were accepting of their care and the healthcare services they receive at SRHB Medical Clinics and the hospital in general.

They had very few complaints or recommendations for improvements. They were complacent. Their care was just "good," things are just okay. In reviewing the literature this is consistent with other research, which finds Aboriginal patient to be typically passive recipients of western medical care (Health Canada, 1999a; Masi, 1989; Smylie, 2000b).

One care provider shares these experiences, which further support these findings.

> When my patients [aboriginal] are discharged I ask them how was it...they say " It was all right, okay…they [SRHB care providers] know better...they're the ones going to be doing it…they know what they're doing…the doctors and nurses.
>
> I encourage them [aboriginal patients] to ask questions…advocate for themselves. I find they are really like…passive when it comes to you know...being in any kind of medical field …lots of elders are so eager to please they are not going to argue with anyone. It is my job…to make sure they understand everything that's happening to them, what the doctors and nurse are saying…doing…making sure it's what they [the patients] want.

Among the Dene, herbal medicines are still used to some extent, particularly by the elders. Traditional practices such as sweat lodges, prayers and sweet grass ceremonies are used. A Dene patient speaks of combining western medicine, his Christian faith and the use of traditional healing practices to support him through his cancer experience.

> For me, the doctors know the cancer, they do the operation and stuff. I got my spirit, my faith in God.

> When I am in hospital you know, the priest came to see me...had mass in the chapel...used sweet grass...it has good power...strong...healing...you know...He [the priest] came lots of times, my family, relatives they prayed for me.

He later shared:

> I have a friend home [small community] and we do the sweats...sweat lodge...some times two three days...it was good for my cancer...get the bad stuff out...

Aboriginal people, both the Inuit and Dene, traditionally had a holistic approach to healthcare in which the body, mind and spirit are treated as integrated parts of the whole. This approach incorporated the belief that a healthy individual is in harmony with their community and with their physical environment. Healing is aimed at treating all aspects of an individual; the physical; spiritual; social and emotional facets of their life. (Lessard, 1994b; Smylie, 2001a)

One Dene man briefly shared a story of a trip he made to Arizona to see a medicine man for his cancer. He said the medicine man gave him hope and the strength to fight his cancer. He also spoke of another pilgrimage he made to a lake in Alberta for a spiritual gathering that strengthened his spirit. He said it is the way of his people to take care of his "whole person" to fight the cancer.

During an interview with a Dene patient she took out a small pouch from her bag which contained dried caribou meat. She also had a container of lard, which she proceeded to spread on the dried meat. Before eating she took out her rosary and said a brief blessing in her own language. Over tea and dried caribou meat she shared her belief that her recovery from her cancer was as much due to her strong faith in God and the healing powers of medicine, which had been given to her by a healer.

This healer had come to her small community and visited all the sick people. She told of the power of his medicine and the ceremony held on the land to make them strong. She was appreciative that the doctor [SRHB Medical Clinics] had cut her cancer out. She regained her strength and will to live from her family and the healer.

While several other aboriginal patients alluded to the use of traditional medicine, healers, and Shamans there seemed to be a reluctance to discuss these in more detail. It became evident throughout the interviews that traditional healing is still important to some of the aboriginal people served by SRHB. These findings are consistent with the literature. The extent of the use of traditional healing in the western arctic is not well known. Available information suggests there is a renewed interest in determining ways to preserve and promote the role of traditional healing practices (GNWTHSS, 2000; Health Canada, 1999a; Royal Commission on Aboriginal Peoples, 1996)

Support: They Were There for Me.

Fitch (2000) reminds us that while cancer patients "receive treatment in hospitals, outpatient clinics and physicians' offices . . . they live with their cancer at home in their own community" (p. 42). When patients were asked the question "What or who supported you when you were diagnosed and being treated for cancer?" each one answered clearly and without hesitation - family and friends. Several spoke at length and with passion of the emotional, physical, psychological, social, financial and moral support they relied on from family and friends.

> My two kids. They have been my strength. When I wanted to give up they wouldn't let me. I am proud of them.

> I couldn't work so I moved in with a friend. They have supported me both financially and psychologically, all the way. They are my family.

> When I needed a shoulder to cry on and an ear to bend she would drop everything and come over. When I had to go to Edmonton for six weeks she came down three times…lucky for me she can do that.

Along with family and friends a number of patients said they relied on other cancer patients for information and support. Some patients said they had spoken with a volunteer support person when initially diagnosed.

Most patients were appreciative of the visit and the support person's offer to be available when they needed anything or if they just wanted to talk. None of the patients I interviewed had taken advantage of the support person's offer for a follow-up visit. Although several patients indicated that perhaps now they were ready and were in a "better frame of mind" to benefit from talking with a support person they felt hesitant or shy to initiate the contact. One patient said:

> Maybe if you had a list of who you can call and phone numbers to give us. I don't think I heard what I was told at first when the support person came...but later on I could have used the help but didn't remember what I was told. Then I sorta thought I wouldn't mind talking to her but...[shrugs shoulders] it would seem strange to call her up now.

In contrast a care provider adds:

> When I have been interpreting for patients they mostly say they want to be left alone. They would rather be with family instead of talking to strangers or taking the treatments.

When asked about the use of community support groups or agencies, very few patients (5/34) said they had made contact with them. Some of the patients could name one support group they were aware of that exists in Yellowknife. One male patient stated " aren't the support groups for women...well at least I think mostly women go to that sort of thing for breast cancer." Based on the characteristics of the sample interview group and their responses, I surmise that patients have limited access to the support groups, which currently exist in the Western Arctic.

Access is further limited if patients live outside of Yellowknife. There are limited support groups in the western arctic and there may be a lack of information about the current support groups that do exist.

Care providers share the following:

> Patients have asked me for the numbers for where they can get information and talk to someone who had gone through this. I found the information for CanSurmount but then I never thought to ask if they ever called or if they did, was it useful.
>
> Patients tell me they want the support of their family, friends, community, and clergymen. I am not sure to what extent they follow through and utilize these services.

The literature supports these findings. In a study focusing on newly diagnosed cancer patients, Whelan et al. (1997) reported that "Despite the fact that the vast majority of patients had identified ongoing problems or concerns, only a limited number reported utilization of community resources. However, most patients identified someone they could depend on" (p. 1523).

In addition to the importance placed on the support of family, friends and community many patients spoke of their appreciation for the support they receive from the medical interpreters provided by Stanton Regional Health Board.

Patients rely on medical interpreters for language interpretation as well as acting as a resource within the hospital and the community.

> __ [Interpreter] picked me up and bring me here [SRHB Clinic] I get lost nice to have someone not so scary.
>
> I understand English good but some things the doctor says it's better to have someone to tell me again in my language.
>
> I didn't want to stay at the boarding home so__[interpreter] got me a place to stay. Better for me. I can walk over here now.
>
> She helped me...she asked to my doctor to have my medicine [herbal tea?] from the medicine man. The doctor told her okay.

Care providers add:

> When the interpreter is not around patients are some times scared or too quiet to ask...like...a lot of them don't know how to use things we take for granted...the call button or mechanisms on a bed...the shower.
>
> They tell us all the time they want us to stay with them, they are scared, they need help...in lots of things...sometimes I bring things for them like caribou or bannock.

Masi (1989) believes the lack of language interpretation services in small communities is a concern. While SRHB has medically trained interpreter services this may not be the case in smaller communities in the Western Arctic. Much of the literature on the subject of language and health care advocates the use of trained interpreter services and cautions against the use of untrained staff, relatives or other patients (Bouvrette, 1994; Lessard, 1994b; Masi, 1992; Penny, 1994; Smylie, 2001b). The issue of the competency of the interpreters was not raised by any of the patients. One patient commented on his discomfort with having a family member interpret and his preference for a male interpreter due to the personal nature of his cancer. Through the male interpreter the patient shared this experience.

> It's good here. He says more private for the things he has to say. He didn't like in the nursing station to have his daughter's girl...she works there...interpreting...he didn't like her to be there when he talked to the doctor. Oh...and he says its better to have a man when it is personal like this.

Care providers expressed their concern over the use of untrained interpreters.

> Sometimes when the family interprets I have been in the room when the patient is told by his family what the doctor said...they just told him he was sick and needed an operation. As a medical interpreter I could understand that the daughter was missing important information about what was going to happen, things he needed to know to understand what would happen.

One care provider suggests:

> They should be invited here [SRHB] the next time language services puts on another module...reach out to the communities...let them know we have trained staff who can help.

Several patients commented on the support they received through the SRHB Medical Travel services. These services are provided to residents of the Western Arctic who do not have employer medical travel benefits. Patients say accessing necessary medical services is made less stressful with the way their travel is organized between Yellowknife and the communities and when necessary between Yellowknife and Edmonton.

> It took a lot of the stress off me having medical travel help make the arrangements. They answered all my questions. Things went very smoothly. They arranged my ticket to Edmonton and for me to be picked up a the airport in Edmonton and taken to Larga House which was great. When I had to go down the next time for six weeks they arranged a condo for me to stay in.

Several patients commented favorably on the work of the SRHB Medical Travel services and the connection they provide to the Northern Health Services Network (NHSN). This is an Edmonton based health care service on contract with the GNWT Department of Health and Social Services. They are a team of nurses who work to coordinate the care of northern patients who are sent to Edmonton for healthcare services. NHSN services are available primarily to NWT residents who are not covered by employer benefit plans.

> The Medical Travel department [SRHB] was great…took a lot of the stress off me...I was already stressed enough. They made all my arrangements and answered all my questions before I left [Yellowknife]. I also had the nurse at the NHSN as a resource and following up with me. It was probably the most important thing to me while I was down there for six weeks.
>
> I don't know what I would have done without the nurses from NHSN. They are lifesavers for any northern patient having to be in Edmonton.

In contrast, patients who are covered under employer health benefits make most of their own arrangements and are not liased with the NHSN services unless they are admitted to an Edmonton healthcare facility. Several patients who used employer paid benefits commented that they felt they had very little support and are isolated and on their own when they are in Edmonton. One patient shares these thoughts:

> I think as government employees we sort of get slipped through the cracks because we are basically on our own…after they [the employer] gives you the authorization you make your own travel arrangements you are told you can stay in a hotel for x number of days and you get so much per day and basically then you are on your own. It would be nice to be able to get the information here from medical travel [SRHB] and get connected when we are in Edmonton to have the number of Northern Health Network Services and encourage outpatients to contact them if they have any problems.

> I was lucky I had someone to stay with and didn't have to stay in a hotel...that would be too much of an experience for me so soon after knowing I have cancer.

Other patients add:

> You know I was there six weeks...different surroundings ...your family wasn't there. So you are alone there is a lot of time to think and worry but if you had somebody else with you, or a contact in Edmonton you would have a more positive experience.

> Being together in a place with other cancer people and other northerners I think would be very supportive rather than being in a hotel.

Care providers confirm what patients have said:

> My ongoing concern is for those patients (or dependants) diagnosed with cancer, that use employer benefits to pay for their Medical Travel. Many of these patients ask about accessing NHSN service. We do not "know" who they are, so we do not offer the full service deal, and I know they fall through the cracks. Unless they are admitted to an Edmonton hospital, the NHSN staff never find out they are in Edmonton, some for lengthy treatments. GNWT employees are not getting the benefit of a GNWT funded program....

Patients along with their care providers interviewed in this study recognize the need for a more comprehensive, integrated cancer care delivery system. This is well supported by the literature. Several Canadian studies call for leadership at the community, territorial, provincial and national level to develop a collaborative strategic approach (Canadian Cancer Society, 1992; Health Canada, 2001b; Ontario Treatment and Research Foundation, 1994).

STUDY CONCLUSIONS

The original question for this research study was:

> From the patients' perspective, what factors contribute to the effectiveness of services offered by Stanton Regional Health Board Medical Clinics to patients living with a diagnosis of cancer in Canada's Western Arctic?

Related sub-questions included:

1. What made you first go to the nurse or the Doctor? Who did you first see?

2. How did you feel when you were first told you had cancer? Who was with you? How were you told? Did you receive enough information?

3. What supported you through the process of being diagnosed and treated for cancer? Who/what helped you? How did you cope?

4. Can you describe what it was like for you to get from place to place to get the care and the help you needed? From your home community. Between SRHB Medical clinics and within Stanton Regional Hospital, Community agencies, Edmonton, transportation.

5. What are the most important things to you in relation to the services and the care that you receive?

6. Can you suggest two or three things that we could have done at this clinic to make it better for you? At the hospital? Outside the hospital?

The results of this research study show from the patients' perspective that there are two main factors, which contribute to effective services offered by Stanton Regional Health Board Medical Clinics to patients living with cancer in the Western Arctic. These are a well-organized, systematic approach to services, and services that are offered within a supportive and caring environment. Most patients seem to believe that many elements of both exist in the current services provided by the SRHB Medical Clinics.

This study demonstrates that access to services offered by the SRHB Medical Clinics is important to patients. Results show that in spite of many patients living in remote and isolated locations in the Western Arctic, patients felt they had very good access to medical services. Patients indicated that over the past twenty years airline service to the smaller and more isolated communities has greatly improved in frequency and reliability.

This is consistent with the research by Ng et al. (1999) suggesting the cost of receiving healthcare in remote areas was not a barrier to access when transportation between rural and urban areas is a factor. While patients do not consider the waiting time to get an appointment with SRHB Medical clinic specialists long, some patients find it stressful living with the fear of a diagnosis of cancer and waiting for the day of the appointment to arrive. Patients appreciate the outreach travel clinics when SRHB specialists provide services in their home community.

Some larger health centers such as Fort Smith, Hay River and Inuvik are equipped to allow the specialists to perform additional tests and procedures that patients may otherwise have traveled to Yellowknife to be performed. Patients are appreciative of this service as it reduces travel time and cost as well as the time away from work and family.

The study showed that for many patients the ability to develop a close and trusting relationship with their healthcare providers is important. This is accomplished over time and with consistent access to the same health care providers. There was some evidence that patients at SRHB Medical Clinics were disturbed by the changes in staff in the clinic over the past few years. Some patients were hesitant to discuss certain issues with anyone other than their regular physician even if it meant a longer wait for an appointment. Other patients accepted the changes as part of the high turnover now being experienced in healthcare. Patient satisfaction is strongly associated with seeing the same doctor or healthcare provider. A continuous relationship promotes trust in the care provider – patient relationship. These findings are supported by the literature (Guthrie, 2000; Sherer et al.1993).

The information gained from this study demonstrates the need for all health care providers to work together more effectively. Patients interface with numerous health care providers and have at best, a vague understanding of a system, which is organized to accommodate care provider schedules and routines. The resulting confusion is not insubstantial. Many patients expressed frustration with the number of care providers involved in their care and the apparent disconnect between the various care provider groups. This study identified some of the contributing factors; miscommunication over patient appointment times, location, or reason for the appointment, missing or incomplete patient information, appointment scheduling, and high patient no show rates. As well there is evidence of the need for improvement in the communication of patient information and the coordination of patient appointments with southern health care facilities such as the Cross Cancer Institute (CCI) in Edmonton. There are indications that care providers in southern facilities may be unaware of the level of services, which can be provided by SRHB. Patients have suggested regularly scheduled oncology services to SRHB.

The potential benefits of this would be: reduced number of follow up visits to CCI for Western Arctic cancer patients, reduced travel time for patients, as well as time off work and time away from their families. There would be the potential to reduce medical travel cost to the NWT healthcare system. As well there may be opportunities for oncology education sessions for patients, public, staff and physicians. Furthermore, visits by a CCI oncologist would promote stronger communication links and a better understanding by the CCI staff of the service capabilities at SRHB and vice versa.

The geographic realities of providing services to Western Arctic patients may also become more evident to care providers from CCI.

The findings of this study indicate a need for a coordinated approach to the delivery of cancer care services in the Western Arctic. This is well supported by the literature (Ford & Fottler, 2000; Gerteis et al. 1993; Guthrie, 2000).

The one thing most patients (33/34) had in common was the fear they felt when they were told they had cancer. Most patients had limited knowledge or previous experience with hospitals, tests and procedures.

Patients want information in order to make informed decisions about their care. When asked, a surprisingly high number of patients (28/34) stated that they felt they had received enough information about their cancer care and treatment. Patients commended care providers for the manner in which information is shared. Although the majority of patients stated they had received what they interpreted as enough information, when they spoke of their actual procedure or treatments or a process in their care, many patients (19/34) identified information they felt they would have benefited from having. This included additional information on treatment and intervention options, getting through the "system", information about their healthcare benefits and information about support groups. This leads me to conclude that patients may not be as well informed as they could be.

The study showed that SRHB Medical clinics are sensitive to the different information needs of their patients. Patients commended care providers for the manner in which they are provided with sometimes unpleasant and difficult information. Patients acknowledged being treated with respect and sensitivity. Patients said they receive most of their information through dialogue with care providers. Patients found care providers were supportive and caring. Some patients rely on other patients with cancer for information and support. Some patients found this to be helpful.

Some patients indicate they were not ready for discussions with a support person or a group but at some point may be interested. Other patients indicated they had no wish to speak with anyone from a support group and their wishes were respected. Research has shown that cancer patients' information needs may vary depending on what stage they are at in their cancer (Ashbury et al., 1998; Canadian Cancer Society, 1992; Fitch 2000). Further research, which focuses on the information needs of cancer patients at the various stages, would be beneficial.

The study shows that patients place a high level of trust and confidence in the knowledge, skills, and abilities of the care providers at SRHB Medical Clinics. A care provider was commended for the thorough and professional approach to care, which instilled a sense of calm and confidence in the patient. Many members of the SRHB Medical Clinics staff were acknowledged for the caring and compassionate manner with which they treated patients at a time when they need support the most.

The study showed that overall patients believe services at SRHB are being provided in a supportive and caring environment. Through the interview process it was clear to me that patients are appreciative of being accepted by health care professionals at SRHB as individuals regardless of their individual values and beliefs.

The study found that patients want care providers to recognize and respect that in their own right, they are the experts in their own disease. There is some evidence, which suggests that when care providers are busy, patients do not get the time needed to have their questions answered. Care providers do not always demonstrate skill and sensitivity towards the cancer patients right and need for hope.

As well patients were sometimes left with the impression that their questions about their care was perceived by health care providers to be challenging their knowledge and authority. In these cases patients felt that care providers were not as sensitive to their needs as they could be.

According to the study, SRHB staff is respectful and open to the unique needs of individuals. Aboriginal patients' stories demonstrated evidence of combinations of western medicine, individual spirituality and traditional medicine used to support patients through their cancer experience.

The study showed that patients rely on the support of family and friends first and foremost. The literature review supports the importance of family and community in the aboriginal culture (Lessard, 1994a; Smylie, 2001b).

Next, cancer patients are said to rely on support from other individuals who have had cancer. Some patients prefer not to discuss their cancer and this decision is respected by the care providers. In addition many patients spoke of their appreciation for the support they receive from the medical interpreters provided by Stanton Regional Health Board. Patients commended the interpreters for not only medical interpretation but also for their assistance with other things such as transportation, accommodations, providing traditional foods and assisting with navigating through the hospital and city.

Patients spoke highly of the support and services they received through the Medical Travel Department of SRHB. These patients appreciated the link to the Northern Health Services Network in Edmonton who act as a liaison and support for all Western Arctic patients who are hospitalized in Edmonton. The study suggests that there is a discrepancy in the support services available to those patients who require outpatient services in Edmonton. Patients who have their medical travel arranged by the medical travel programs of each of the health boards are linked to NHSN as a resource and support. In contrast, patients with *employer provided* medical benefits must make their own travel arrangements and do not have access to these NHSN services. Several patients requested the ability to access the services of SRHB Medical travel and NHSN, as there are no other support mechanisms available to them while in Edmonton.

Patients along with their care providers interviewed in this study recognize the need for a more comprehensive, integrated cancer care delivery system. This is well supported by the literature.

Several Canadian studies call for leadership at the community, territorial, provincial and national level to develop a collaborative strategic approach (Canadian Cancer Society, 1992; Health Canada, 2001a; Ontario Treatment and Research Foundation, 1994).

In conclusion this study revealed that overall, patients are satisfied that services within SRHB Medical Clinics are provided in a systematic, organized manner within a supportive and caring framework. The study further demonstrates that while the services provided by SRHB Medical Clinics work well, there are areas for improvement.

From the data gathered throughout the research, the following summarizes the main conclusions regarding the factors, which contribute to the effectiveness of services provided to SRHB Medical Clinic to patients living with cancer in Canada's Western Arctic.

1. Services must be accessible and provided in the most appropriate location as close to the patient's home community as possible. The study found that although more than half the patients interviewed live outside of Yellowknife they feel they have good access to services provided through SRHB Medical Clinics.

2. The continuity of care is essential to developing a positive trusting relationship between the care provider and the patient.

3. Care must be co-ordinated between SRHB Medical Clinics and other SRHB units, their family physicians and health centers in their home communities as well as between SRHB care providers and health care providers in "the south." This will provide a more comprehensive, integrated cancer care delivery system.

4. Information must be provided which meets patients' needs in order for them to be a fully informed and an equal partner in the decision-making process regarding care.

5. Patients want care providers they believe to be knowledgeable, skilled, caring and compassionate. Care providers must not destroy cancer patient's hope.

6. Respecting the individual, their values, and beliefs must be incorporated into care delivery. Listening and learning from cancer patients is needed in order to work towards continued improvements in cancer care.

7. Patients rely first and foremost of the support of family and friends.

STUDY RECOMMENDATIONS

Act

This next step in Stringers' (1996) cyclical action research process is "acting on what has been learned to formulate practical solutions to the problems perceived" (p. 97). The following recommendations reflect the common threads of the stories of the thirty-four cancer patients living in the Western Arctic and receiving services for their cancer through the Stanton Regional Health Board Medical Clinics. The stories of these patients were validated by a group of their care providers. These recommendations are a blending of their insights. Representatives from the patients who were interviewed, the focus group, the staff of the SRHB Medical Clinics and the Medical Director, as the organizational sponsor for this study, reviewed a draft of these recommendations.

Based on the data, the research process and the conclusions drawn, two main recommendations are offered for consideration. These are suggested general actions that Stanton Regional Health Board might consider undertaking. Each represents an organizational implementation that requires leadership and the collaboration between Stanton Regional Health Board Medical Clinics and all stakeholders engaged in the provision of services to cancer patients.

Recommendation #1:

Establish a Cancer Care Program at Stanton Regional Health Board.

1. The breadth and complexity of the needs of cancer patients in the Western Arctic require that a range of disciplines and organizations work together to provide necessary services. It is recommended that Senior Management of Stanton Regional Health Board endorse the transition of services currently being provided to cancer patients in a fragmented and ad hoc manner to a recognized and organized Cancer Care Program. This endorsement will provide the necessary leadership and support needed to maintain the current momentum of service delivery and advance cancer care services at SRHB to the next level, one which is co-ordinated, integrated and provided in a supportive environment.

2. Leadership at the Senior Management level is required to ensure support for the Cancer Care Program. A Steering Committee should be formed to provide an umbrella structure, which will integrate representatives of the various stakeholders providing cancer services both inside and outside the organization. This committee would be responsible for the development of the philosophy and principles of cancer care as a foundation for program development. This committee will set policy and direction for a program framework, which is consistent with the SRHB quality management philosophy (SRHB Quality Management Program, 1998).

As well. cancer care is one of the key components of the accreditation requirements by the Canadian Counsel on Health Services Accreditation (Stanton Regional Health Board Accreditation Task Force Manual, 2001a).

3. It is essential to make the best use of resources therefore whenever possible SRHB should make use of existing committee structures and work groups.

4. The co-ordination of services provided to Cancer patients by the Alberta Cancer Board is essential. There should be a formalized relationship between SRHB and the Alberta Cancer Board. This will provide a mechanism to improve communication and coordination of services.

5. There are currently limited mechanisms in place, which allow for the communication and collaboration between SRHB and the various cancer organization and volunteer groups in the Western Arctic. SRHB should strengthen its relationship with cancer care agencies and cancer volunteer groups within the community. This could be accomplished through representation on a steering committee.

6. The Cancer Care program will require a mechanism to report activities as it moves through the quality management cycle. Senior management should consider the role of the Cancer Care Program and it's reporting relationship within the organization. One suggestion would be to report to the SRHB Clinical Practice Advisory Committee or the Quality Management Committee.

Recommendation #2:

Foster a supportive care environment for the provision of services to cancer patients by improving the co-ordination of services, providing appropriate information, and continuing to respect the uniqueness of cancer patients' needs, values and beliefs.

These components of a supportive care environment are listed in order of priority as suggested by the study findings.

Improving the co-ordination of services

1. Under the direction of the Cancer Care Steering Committee a Working Group should be formed to co-ordinate the development of the Cancer Care Program. To assist with the development of the Cancer Care Program, the Coordinator of Planning and Development for SRHB should facilitate this process.

2. The Working Group will draw on the substantial knowledge and experience of key stakeholder and professional representatives, as well as that of recognized experts working in areas related to cancer care. This research study has already brought together many of the stakeholders with an interest in a co-ordinated Cancer Care Program.

3. Suggested representation could include family physicians and specialists who see the majority of cancer patients, nurses both on the units and in ambulatory and clinical settings, social worker, clergy, rehabilitation specialists, palliative care, ethics committee representation, pharmacy, radiology, laboratory, dietary, chemotherapy nurses, physicians, interpreter services and medical travel. There should be a mechanism whereby the Working Group has representation from external stakeholders when appropriate.

4. In developing the Cancer Care Program, the Working Group should undertake a variety of activities from developing a current service inventory, identifying and analyzing current gaps and needs, summarizing relevant issues and opportunities for action, potential costs and benefits of various interventions and making recommendations to Senior Management for further action. Once issues and priorities have been identified sub-working groups of the appropriate stakeholders will be required to work on specific priorities and the quality cycle begins once again.

5. Using a program model which follows the quality management cycle, will ensure persons affected by cancer receive the care and services they require; provide guidance for appropriate program planning and development and assist health care providers in providing continuity of care. The model for gynecological oncology care in the Ob/Gyn program has provided consistent and reliable services for over twenty years. Other SRHB programs may be able to adopt some elements of success of this model.

6. The co-ordination of medical appointments at SRHB will decrease the frustration of both patients and care providers. SRHB Medical Clinics should identify, document and analyze gaps in the coordination of patient appointments such as errors in appointment times, care providers or location of service. This data should be analyzed and action plans developed to address the identified issues.

7. Computerized appointment scheduling for SRHB Medical Clinics is required. There should continue to be strong support by Senior Management for the Information Management Strategic Plan's goal for the automation of patient information systems especially patient appointment scheduling in the Medical Clinics and Medical Travel scheduling.

8. Cancer patients and care providers would benefit from scheduled visiting oncology service. SRHB should explore the option of visiting oncology services.

Providing appropriate information in a timely manner

1. Information and support is essential for cancer patients. SRHB Medical Clinics should identify, document and analyze gaps in the information needs of cancer patients. This may include information regarding their cancer diagnosis, treatment options, and preparation for test or procedures. This data should be analyzed and action plans developed to address the gaps in information. Information should be available in plain language and in format that is user friendly.

2. Understanding the "big picture" of what is going to happen next is important to many cancer patients. SRHB Medical Clinics in consultation with other stakeholders should prepare a flow chart showing the potential steps a patient may take in their cancer care continuum. This would provide a visual illustration of the path a patient may journey within SRHB, between SRHB and the community and SRHB and cancer care facilities in Edmonton.

3. Access to support services is particularly important to cancer patients when they are required to be in Edmonton for extended periods of time. SRHB should explore the option of making the services of the SRHB Medical Travel Department and the Northern Health Services Network in Edmonton available to all SRHB cancer patients required to travel for medical services.

4. Individual cancer patients require the support provided by other cancer patients at different times along the continuum of care. SRHB Medical Clinics should work with key stakeholders to develop a resource contact list for patients to access support persons who are trained to provide information, encouragement and emotional support.

5. SRHB Medical Clinics should designate an individual at each clinic location to be a liaison with community cancer volunteer groups.

Continue to respect the uniqueness of cancer patient's needs, values and beliefs.

1. Training for care providers in oncology is essential. To provide optimal outcomes in the provision of cancer care services all staff in the facility who work with cancer patients should have oncology-specific education and training. The curriculum should be based on best evidence or where available national standards of practice.

2. Over half the patients served by SRHB are of Aboriginal heritage. Qualified medical interpretation services are essential to ensure Aboriginal cancer patients of SRHB Medical Clinics have informed consent regarding their medical treatments. A good working relationship with the interpreters is essential. SRHB should include interpreter services as guest speakers at staff meeting twice a year.

3. A good understanding and appreciation by care providers at SRHB for the Aboriginal holistic approach to health is vital. SRHB should respect the traditional medicine practices of Aboriginal patients and work with Aboriginal groups to find way to integrate traditional and western medicine.

CHAPTER 5 – RESEARCH IMPLICATIONS

Organizational Implementation

Act

Stanton Regional Health Board Medical Clinics currently provide a broad range of services to patients diagnosed with cancer and living in the Western Arctic. For many of these patients, there is a wide spectrum of experiences and interactions with the healthcare system. The main purpose of this study was to learn about the lived experiences of these patients and determine what is important to them in terms of the services they receive from SRHB Medical Clinics. The information gathered in this study is being used to inform SRHB Medical Clinics, the SRHB Senior Management Team and other areas which were identified in the course of the study about cancer patients' experiences, their needs and what can be done to provide more effective service.

To begin the process of acting on these recommendations I will present the findings of this study and the recommendations to the SRHB Senior Management Team for consideration. I will also develop an action plan to include goals, measures, targets, time frames and outcomes. This will be reported through the Quality Management cycle.

Endorsement to Establish a Cancer Care Program

Endorsement by Senior Management for the establishment of a Cancer Care Program must be received prior to any planning activities. There is compelling evidence presented in this study, which supports the need for a Cancer Care Program at SRHB. In addition to the current status of cancer services at SRHB, the incidence of cancer in Canada is predicted to more than double over the next fifteen years (National Cancer Institute of Canada, 2000). Following the endorsement by Senior Management, it is recommended that the Coordinator of Planning and Development for SRHB be asked to facilitate the program development process.

If SRHB is to deliver cancer care services to these patients there will need to be a co-ordinated approach to minimize the impact of the anticipated increases in the demand for treatment and supportive care. Results of this study show that although patients are generally pleased with the services provided by SRHB Medical Clinics and other individual disciplines there is an identified need for the improved co-ordination and integration of these services.

For the past several years there have been discussions underway to develop a relationship with the Alberta Cancer Board (ACB). A group of representatives from SRHB and ACB was initially formed to provide a mechanism to discuss and develop the chemotherapy services at SRHB. One option would be to have this group broaden its' focus and take on the role as the Steering Committee.

Without the endorsement by Senior Management to move to an organized program approach, cancer services will remain fragmented and uncoordinated.

There will be lost opportunity to streamline and improve services to cancer patients, develop partnerships with community groups as well as streamline services between SRHB and the Alberta Cancer Board. With the projected increase in the number of cancer patients who will require services there will be additional strain on an already over burdened system.

Improving the Co-ordination of Services

One of the virtues of action research is its responsiveness to the data. The cyclic process allows this to happen more easily than in other methods of research. If each step is preceded by planning and followed by review, learning by the researcher and client is greater. (Dick, 1999). Mid-way through the data gathering stage it became apparent to me that the co-ordination of medical appointments at SRHB were causing frustration for both patients and care providers. SRHB Medical Clinics staff have begun to gather data on this issue. The next step will be for the SRHB Medical Clinic staff to work together to analyze the data, identify the issues and develop an action plan to improve services. I will then report this activity through the Quality Management committee. Mechanisms have been put in place to monitor and evaluate the outcome of the action plan. As well, during the data gathering stage there were two issues that arose that involved patient care services in other areas of the hospital. In both instances the patients agreed to a meeting with the manager of the identified areas to assist with the problem solving process. By putting processes in place to address these issues action is taken in a more timely manner.

Computerized appointment scheduling has been a goal of the SRHB Medical Clinics for approximately five years. In January of 2001 SRHB committed to doing a needs assessment in the spring of 2001. The findings of this study will provide additional substantiation to the request. As a member of the Information Management Committee I will present the findings of this study and continue to lobby for support. The implications of not having a computerized scheduling system is evidenced through the patients' stories which tell of the lack of easy access to basic patient information, time consuming manual processes, and inability to track patient appointment activities. This will continue until an appointment scheduling system is in place.

The request for visiting oncology services to SRHB will be followed through on several fronts. From the meetings with the Alberta Cancer Board last fall there have been indications of interest in having an oncologist come to SRHB this summer. It will also be identified through the development of the Cancer Care Program. The implications of not having visiting oncology services would mean status quo with the reduced potential to increase communication and the coordination of services between the SRHB and the CCI.

Providing Appropriate Information in a Timely Manner

Information and support is essential for cancer patients. SRHB Medical Clinics will undertake to identify, document and analyze gaps in the information needs of cancer patients. This may include information regarding their cancer diagnosis, treatment options, and preparation for test or procedures.

This data will be analyzed and action plans developed to address the gaps in information. As part of the process a flow chart will be developed in consultation with other stakeholders. This would provide a visual illustration of the path a patient may journey within SRHB, between SRHB and the community and SRHB and cancer care facilities in Edmonton.

SRHB Medical Clinics will work with key stakeholders to develop a resource contact list for patients to access support persons who are trained to provide information, encouragement and emotional support. SRHB Medical Clinics will designate an individual at each clinic location to be a liaison with community cancer volunteer groups.

These initiatives will contribute to improved access to information and support for cancer patient served by SRHB Medical Clinics.

Continue to Respect the Uniqueness of Cancer Patients' Needs, Values and Beliefs.

Training for care providers in oncology is essential. The findings of this study will be presented to the Education and Language Services Department to incorporate oncology education into the SRHB educational plan. Without oncology training care providers are not as well prepared to support patients in a consistent manner. This inconsistency may compound stress placed on care providers who may not possess the skills to assist patients with some of the complex issues they face.

The opportunity to work with Aboriginal medical interpreters and the Aboriginal patients contributes to the richness of the organizational culture at SRHB Medical Clinics. An invitation has been extended to the Education and Language Services Department to attend an upcoming SRHB Medical Clinics meeting. The purpose will be to listen and learn, and share stories, thoughts and ideas on the improvement of information services to aboriginal patients. It was evident through this study that there is a need to recognize traditional medicine practices of Aboriginal patients and work with Aboriginal groups to find ways to integrate traditional and western medicine practices at SRHB. These findings will be shared with the Education and Language Services department for further consideration.

The implications of not having culturally appropriate services available to aboriginal patients would contribute to the ethnostress or the negative experiences felt when members of different cultures interact (Antone et al., 1986; Smylie, 2001b). As well there is a high risk that aboriginal patients would not be informed about their medical treatment.

Future Research

This research study represents the recursive cyclical nature of action research. The focus of this study was to determine what factors contribute to the effectiveness of services provided to patients living with cancer in Canada's Western Arctic. The goals of this study have been met only to lead to other questions that require further research.

Very early on in the data gathering it became evident that patients and care providers are frustrated with the coordination of patient scheduling. Based on this data, a research project has begun to determine what factors contribute to the poor coordination of patient appointments at SRHB Medical Clinics and how we can improve.

Other potential questions to be answered are:

- What are the supportive care needs of patients in the Western Arctic?
- What are the supportive care needs for men versus women in the Western Arctic?
- What are the information needs of selective Aboriginal groups?
- What is the most effective method of communicating information to Aboriginal patients in the Western Arctic?
- What impact does the level of education have on the information needs of cancer patients in the Western Arctic?
- What is the impact of the socioeconomic status on coping with cancer?
- What are the information needs of a newly diagnosed cancer patient?
- What are the traditional medicine rituals currently practiced in the Western Arctic? How can these practices be incorporated with western medicine?

CHAPTER 6 – LESSONS LEARNED

Research Project Lessons Learned

- During the conduct of this research study I experienced a wide range of emotions. At times I felt confident that I had a clear vision of where I was going and what I was doing. Equally as often I felt overwhelmed, confused, scared, and frustrated. Through all of this I learned the value of investing the time up front to cultivate support for my research. Support from the organization, my peers, and the participants in the study along with family and friends were key in motivating me keep moving forward.

- Qualitative research and story telling are excellent ways to collect data. They are also very time intensive. While it is very interesting and often captivating to hear the rich details of individual experiences it is also very important to find the balance between stories which are interesting and stories which will give you useful data to answer your research question. I think I learned this after the fifth two-hour interview when I was reviewing the transcripts and audiotapes. I really had to search through the stories to pick out the real meaning of what the participants were telling me. I learned to focus and not to get sidetracked.

- I facilitated a focus group of colleagues and peers on a work related issue a month or so prior to conducting the focus group session for this study.

- I learned that as the facilitator it is very easy to get off track or become part of the discussions especially if it is with colleagues or peers you are comfortable with, and it is a topic you are passionate about. It was a good lesson and helped me to avoid the same pitfalls when conducting the research focus group session for this study.

- After reviewing my notes and listening to the audio recording of the focus group session I felt that I had done a good job of facilitating the session and keeping the focus on the patient's perspective. I learned that I cannot listen to discussions and take good notes at the same time. This is why audio taping interviews becomes a lifesaver.

- In retrospect I would get as much of my literature review done during summer residency as I could. Research is much easier to do when you are on vacation from your real life.

- I learned that although I can listen with an open mind and an open heart, I do not know or understand what it is like to be diagnosed with cancer. Overall I feel a great sense of satisfaction in this study's outcomes, in the knowledge I have gained and the relationships I have developed. I have been a humbled and privileged listener.

Program Lessons Learned

1. (1c) Provide leadership

The opportunity for me to develop and conduct this research study throughout this past year has allowed me to demonstrate my leadership skills. I was able to identify an opportunity within our organization and suggest an approach to further develop it. I shared my proposal with key stakeholders, asked for and received their support.

The methodology chosen required that I be able to develop an open and comfortable relationship with the one-to-one interview participants as well as key care provider in order to gather relevant data to answer the research questions. I was also able to lead a focus group process as a means to gather data to validate the stories of the interview participants. I used facilitation skills and communication skills to lead effective groups and one-to-one interviews, which provided me with data that was relevant to my study. I kept participants and my sponsor informed of the progress of the study. I also welcomed all opportunities to discuss the study, answer questions and hear the thought and ideas of others.

2. (2b) Apply systems thinking to the solution of leadership and learning problems

This study was conducted using a systems thinking approach. Data was gathered from multiple sources. In my method of data collection I tried to ensure the sample group was geographically and culturally representative of the population served by SRHB Medical Clinics.

The focus group was structured to include a wide range of care providers. The literature review focused on the key domains that might assist to confirm or refute the study findings. My study conclusions and recommendations for implementation involve the organization as a whole, the community and other external partners.

3. (5a) Identify, locate and evaluate research findings

I was able to identify, locate and review the literature, which I believe was comprehensive and relevant to my study. I was therefore able to use this literature review to compare it to the data I gathered through interviews and focus groups. This allowed me to draw conclusions about the validity of the research findings.

4. (5b) Use research methods to solve problems

This was a qualitative, inductive action research study seeking to address a particular issue in the organization I work for. Using an action research methodology allowed me to simultaneously develop an understanding of the issues, identify opportunities for change and take action. The use of one-to-one interviews, a focus group of care providers and the review of key domains of the literature was an appropriate mix of methods for this type of research. Involving key stakeholders to find solutions to the issues increased the likelihood that the suggested recommendations will be successfully implemented.

5. (7b) Communicate with others through writing

This final report demonstrates my ability to communicate with others through writing. Additional examples of written information, which I developed to help inform participants prior to the interview or the focus group sessions, are appended.

Research participants indicated this information was clear and understandable. Medically trained interpreters translated this information orally to Aboriginal or Inuit participants. Through the interpreter participants indicated they understood the information, which had been translated.

6. (1e) Recognize ethical considerations

I ensured the ethical principles were honored throughout the process of the study by adhering to the guidelines established by the SRHB Ethics Committee and Royal Roads University. This included the use of the informed consent, protection of the confidentiality of the participants and the confidentiality of the data. To avoid an ethical conflict in this study I respectfully declined the offer of a few potential participants with whom I had already spoken with about local cancer services, feeling that these conversations may have biased my views.

7. (3c) Create and lead team

As part of this research study I successfully lead the staff of the SRHB Medical Clinics through each step of my study so they were aware of the process and the progress. I used this team to ask questions, discuss issues and obtain feedback on all aspects of the study. This helped to create awareness of the issues as well as the process and in turn develop ongoing support. As well,I created an ad hoc team of care providers to participate in a focus group session. Leading this session required facilitation skills to keep the discussions focused and obtain the data to answer the research question.

8. (3d) Evaluate and plan ones future within an organization

Following the completion of this study I will present the findings and recommendations to the senior management team of the Stanton Regional Health Board. An action plan based on the conclusions and recommendations from this study will be developed. These actions and the outcomes will be reported and monitored through the quality management process at Stanton Regional Health Board.

9. (4a) Assess the implications of the learning environment

Completing this research study has provided ongoing learning opportunities. The review of the literature allowed me to learn from previous research about health care in remote and rural areas, culture and healthcare, client centered approaches to health care and supportive care for cancer patients. Learning to be more of an active listener proved to be valuable and it is a skill I will continue to improve. Although I learned research is not difficult, it is a slow, time consuming process and requires a well-structured framework to guide the researcher. Data analysis requires reading, re-reading, looking for and interpreting themes, and then attempting to relate those themes back to the literature. I believe the greatest implication on the learning environment has been the demystifying of the research process and fostering interest in future learning and research.

10. (4e.) Help others learn

The progress of this research study was a standard agenda item for information and discussion at monthly SRHB Medical Clinics staff meetings. This provided an opportunity to share with the staff in the SRHB Medical Clinics; the learning gained from the literature review and the research process itself. It provided an opportunity to explain qualitative research and the action research process. As in the cyclical action research process the end of this study becomes the beginning of the next cycle of action as SRHB Medical Clinics staff develop plans to address the issues we have identified. We continue to learn.

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Invitation to Participate in a Research Study
About
The Experience of Living with a Diagnosis of Cancer in Canada's Western Arctic

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Have you had a diagnosis of cancer in the past three years? Have you received services through one of the programs at Stanton Regional Health Board Medical Clinics? If you have, I would like to speak with you!

Introduction and Background

I am doing a research project in partnership with Stanton Regional Health Board and Royal Roads University as a partial requirement to complete my Master of Arts Degree in Leadership and Training. The project I have chosen is to determine what factors would contribute to the effectiveness of services offered by Stanton Regional Health Board Medical Clinics to individuals living in the NWT with a diagnosis of cancer.

Anticipated Benefits of this Project

Your participation will provide Stanton Regional Health Board, the researcher, participants and society at large with an opportunity to:

- Appreciate what it means to live with a diagnosis of cancer in an isolated part of our country.
- Understand what it is like to navigate through our healthcare system - between the various services within Stanton Regional Hospital, your family doctor or nursing station, community agencies as well as services you may have received in Edmonton.
- Identify opportunities to strengthen linkages with other agencies involved in providing services to cancer patients and;
- Determine what we can do to provide care that is culturally appropriate, supportive and focused on the needs of the individual.

Who are the participants?

I am looking for cancer patients who have received services at the SRHB Medical Clinics over the past three years, with a year or more since their date of diagnosis to participate in this project. The participants who accept the invitation to participate in a personal interview will be representative of the geographically and culturally diverse population served by SRHB. The participants will have lived in the NWT or the Kitikmeot region of Nunavut from the time of their diagnosis until the present time.

Appendix A-1

Invitation to Participate in a Research Study...continued

What will your participation involve?

The interview will last approximately 60-90 minute and will be scheduled at a mutually convenient time and place. You participation is entirely voluntary and every effort will be made to keep your participation confidential. You are free to withdraw at any time during the process. The interviews will be audio taped. You can ask for the audio recorder to be turned off, and/or for the notes to be destroyed. Your information will remain confidential. Every effort will be made to ensure there will be no information that may identify you as a participant. There will be no names in the document. Notes and recording will be kept in a secure place and destroyed when the study has been completed. The attached consent form provides further information

You will have an opportunity to review the draft document to ensure you are comfortable with the information you have shared and that your thoughts are accurately reflected. Follow-up summaries will be offered to all participants once the study is completed.

Thank you for considering my request. I hope you will agree to be a part of this project. Your participation will provide an important contribution to helping health care providers understand the experiences of individuals living with a diagnosis of cancer, in the NWT.

If you have any questions about this project and your potential role in it or are willing to participate, please contact me through one of the various means listed below.

Sincerely,

Ruth A Robertson, RN
MA (Candidate)
Stanton Regional Health Board

Dr. Pierre Lessard
Project Sponsor
Stanton Regional Health Board

Work: (867) 669-4146
Fax: (867) 669-4139
Work E-Mail: ruth_robertson@gov.nt.ca
Home: (867) 873-3240 (collect if long distance)
Home E-Mail: st8akaos@theedge.ca

Appendix A-2

Invitation to Participate in a Focus Group About Patients Experiences Living with a Diagnosis of Cancer In Canada's Western Arctic

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Introduction and Background

I am doing a research project in partnership with Stanton Regional Health Board and Royal Roads University as a partial requirement to complete my Master of Arts Degree in Leadership and Training. The project I have chosen is to examine the experiences of cancer patients living in Canada's western arctic and accessing care through the health care system. For the purposes of this project the western arctic refers to the NWT and the Kitikmeot region of Nunavut.

It is anticipated that this information will assist in determining what factors would contribute to the effectiveness of services offered by Stanton Regional Health Board Medical Clinics to individuals living in the western arctic with a diagnosis of cancer.

Benefits of this project

As a care provider, your participation will provide Stanton Regional Health Board with an opportunity to:

- Appreciate what it means for patients to live with a diagnosis of cancer in an isolated part of our country.
- Understand what it is like to navigate through our healthcare system - between the various services within Stanton Regional Hospital, the family doctor or nursing station, community agencies as well as services cancer patients may have received in Edmonton.
- Identify opportunities to strengthen linkages with other agencies involved in providing services to cancer patients and;
- Determine what we can do to provide care that is culturally appropriate, supportive and focused on the needs of the individual cancer patient.

Who are caregivers?

Participants for this focus group will be SRHB staff that has provided care to cancer patients over the previous three-year period of time. This time frame was selected to allow for sufficient experience with cancer patients in the NWT health care system. This will include representation from the SRHB physician specialists group, nurses in the SRHB Clinics, Medical Day Care staff, Diagnostic and Therapeutic Services, Social Work, Homecare, Language Services and Medical Travel Staff.

What I need from you?

I am looking for SRHB care providers to volunteer to participate in a focus group session. The purpose of this session is to find out what cancer patients have shared with you regarding their experiences with living in the NWT and accessing healthcare services.

Methodology

You participation is entirely voluntary. As an employee of SRHB whether you choose to participate in the focus group or not will have no adverse affect upon your employment or advancement with SRHB. Only other participants in the focus group, the researcher and the project sponsor will know of your participation in this group. Outside of the focus group your participation will be kept confidential. Any information you provide will remain confidential. You are free to withdraw at any time during the process. You can ask for the tape recorder to be turned off at any time, and/or for the notes to be destroyed. There will be no names in the document. Every effort will be made to ensure there will be no information that may identify you as a participant.

The focus group session will last approximately 60- 90 minute and will be scheduled during the month of February 2001. The interviews will be tape-recorded. Notes and recording will be kept in a secure place and destroyed when the study has been completed. The attached consent form provides further information.

The final report will be ready in May 2001, at the earliest. A copy of the final report will be housed a Stanton Regional Health Board and at Royal Roads University.

Thank you for considering my request. I hope you will agree to be a part of this project. Your participation will provides an important contribution to helping understand the experiences of individuals living with a diagnosis of cancer, in the NWT and identifying potential improvements to the system.

If you have any questions about this project and your potential role in it or are willing to participate, please contact me.

Sincerely,

Ruth A Robertson, RN
MA (Candidate)
Stanton Regional Health Board
Work: (867) 669-4146 Fax: (867) 669-4139
Work E-Mail: ruth_robertson@gov.nt.ca

Dr. Pierre Lessard
Project Sponsor
Stanton Regional Health Board

Appendix B-1

Information for Interview Participants

Project Title: **Living with a Diagnosis of Cancer in Canada's Western Arctic**

Researcher: Ruth Robertson, Masters Student, Royal Roads University
Contact Numbers: Work: (867) 669-4146
Fax: (867) 669-4139
Work E-Mail ruth_robertson@gov.nt.ca
Home: (867) 873-3240 (collect)
Home E-Mail: st8akaos@theedge.ca

Faculty Supervisor: Fred Jacques, MA.
Faculty of Management
University of Calgary
Contact Numbers: Work: (403) 251-9608
Fax: (403) 251-9814
E-Mail: fjacques@netcom.ca

Please read these pages carefully. Your signature indicates you consent to participate in this study, which will follow the methods described below.

Background

You will participate in a research study to determine what factors would contribute to the effectiveness of the services offered by Stanton Regional Health Board Medical Clinics to individuals living with a diagnosis of cancer in a remote area of our country

Anticipated Outcomes/Benefits

The outcome of this study will provide Stanton Regional Health Board, the researcher, the participants and society at large with:

- An appreciation for what it means to live in the NWT with a diagnosis of cancer
- An understanding of what it is like for our patients to navigate through our healthcare system;
- An opportunity to identify areas to strengthen linkages with other healthcare partners and community agencies involved in providing services and;
- Opportunities to determine what we can do to provide service that are culturally appropriate, supportive and focused on the needs of the individual.

Information for Interview Participants

Method:

- All information, data, and conversations will be kept confidential.

- Participation is voluntary and you may withdraw at any time.

- Your participation is anonymous. The researcher and the project supervisor are the only individuals that will know of your participation. You will not be identified by name throughout the research notes or final document. To maintain your anonymity, you will be identified through out the research by a pseudonym.

- You will be interviewed and asked questions regarding your thoughts, feelings and experiences. Each interview will last approximately 60 to 90 minutes. The interviews will be taped and transcribed.

- You may refrain from answering any questions that you prefer not to answer, or stop the interview at any time. You may also ask to have the tape recorder turned off at any time, or to request that the tape not be transcribed.

- Once the tapes are transcribed, a transcript of the discussion will be sent to you to verify that I have accurately heard and what you told me. Once you have verified the discussion, I will erase the tapes.

- Participant consent forms will be kept for one year and then destroyed in accordance with the SRHB Ethics Policy.

- There will be no monetary compensation to you for participating in this study. However, you may obtain a full report of the research results, free of charge, by completing the request section at the end of this consent form. The report will be ready in May 2001, at the earliest. In addition a copy of the final report will be housed at Royal Roads University and the library at Stanton Regional Hospital.

- The data from this research project may also be used in articles submitted to professional journals or presentation at health conferences. Again, the same standards of confidentiality and anonymity will be maintained.

- Whether you choose to participate in this research or not will have no effect upon the medical care or services that you receive or are to receive.

- No deception will be used at any time in this study, and the research team will endeavor to ensure that no harm of any kind will come as a result of your participation in this study.

Appendix B-1

Information for Interview Participants

The Ethics Committee at Royal University and the Ethics Review Committee at Stanton Regional Health Board have approved this research project. If you have any questions regarding the ethical nature of this project please contact:

Karen Hoeft, Chairperson, SRHB Ethics Committee
(867) 920-4673

If you have further questions or concerns regarding participation or for verification of authenticity of this project please contact:

Fred Jacques, Faculty Advisor
(403) 251-9608 e-mail fjacques@netcom.ca

If you have further questions concerning matters related to this research, time frames or expectations please contact:

Ruth Robertson (researcher)
(867) 669-4146 or 873-3240 evenings and weekends e-mail st8akaos@theedge.ca

Request for a copy of the final report

If you would like a copy of the results, please complete this section.

Name: ______________________________

Address: ______________________________

Postal Code: ______________________________

Phone: ______________________________

CONSENT FORM - INTERVIEW PARTICIPANT

(The "Information Sheet" must be attached to this consent form and a copy given to the Research subject)

Part 1 (to be completed by the Principal Investigator):

Title of Project: Living with a Diagnosis of Cancer in Canada's Western Arctic

Principal Investigator(s): Ruth Robertson Phone Number(s): (867) 669-4146
Co-Investigator(s): N/A

Part 2 (to be completed by the research subject):

	YES	NO
Do you understand that you have been asked to be in a research study?		
Have you read and received a copy of the attached information sheet?		
Do you understand the benefits and risks involved in taking part in this research study?		
Have you had an opportunity to ask questions and discuss this study?		
Do you understand that you are free to withdraw from the study at any time, without having to give a reason and without affecting your future medical care?		
Has the issue of confidentiality been explained to you, and do you understand who will have access to your medical records?		
Do you want the investigator(s) to inform your family doctor that you are participating in this research study?		

Who explained this study to you?

____

I agree to take part in this study: YES ☐ NO ☐

Potential Risks

The researcher acknowledges that living with cancer is a personal and sensitive issue for the patient. The potential that this interview may evoke unresolved thoughts, feeling and issues is very real. The researcher will be sensitive to this potential. Should this occur the researcher will provide the participant with information regarding resources that may be available to assist the individual.

No deception will be used at any time in this study. The researcher will endeavor to ensure no harm of any kind will come as a result of participation in this study. Interview participants may potentially fear that if they participate in this research or choose not to participate that it may have an impact on the medical care or services that they receive or will need to receive in the future. It will be very clearly stated in writing and reinforced verbally that the individual's decision to participate or not to participate will in no way have any effect on their care or treatment.

Signature of Research Subject: ____________________________________

(Printed Name): ____________________________________

Date: ____________________________________

Signature of Witness: ____________________________________

Signature of Investigator: ____________________________________

Signature of Interpreter (if required): ____________________________________

(Printed Name): ____________________________________

Appendix B-3

Information and Consent Form – Focus Group Participants

Research Project Title

Living with a Diagnosis of Cancer in Canada's Western Arctic

Researcher: Ruth Robertson, Graduate Student, Royal Roads University
Contact Numbers: Work: (867) 669-4146
Fax: (867) 669-4139
Work E-Mail ruth_robertson@gov.nt.ca
Home: (867) 873-3240 (collect)
Home E-Mail: st8akaos@theedge.ca

Faculty Supervisor: Fred Jacques, MA.
Faculty of Management
University of Calgary
Work: (403) 251-9608
Fax: (403) 251-9814
E-Mail: fjacques@netcom.ca

Please read these pages carefully. Your signature below indicates you consent to participate in this study, which will follow the methods described below.

Background
The Western Arctic is a vast geographical region covering approximately one quarter of Canada's landmass. Small isolated communities, diverse cultures, scarce resources and an overwhelming number of significant social and health issues limit the capacity of many of the communities to readily meet healthcare needs of cancer patients.

Purpose
The purpose of this study will be to describe, from the cancer patients' perspective, their experience with navigating through the Northwest Territories (NWT) health care system to access necessary medical treatment. Your participation in this research study will assist to determine what factors would contribute to the effectiveness of the services offered by Stanton Regional Health Board Medical Clinics to individuals living with a diagnosis of cancer in this remote area of our country.

Anticipated Outcomes/Benefits
The outcome of this study will provide Stanton Regional Health Board, the researcher, the participants and society at large with:

- an appreciation for what it means to live in the NWT with a diagnosis of cancer
- an understanding of what it is like for our patients to navigate through our healthcare system;
- an opportunity to determine what we can do to provide service that are culturally appropriate, supportive and focused on the needs of the individual and;
- an opportunity to identify areas to strengthen linkages with other healthcare partners and community agencies involved in providing services

Appendix B-3

Information and Consent Form - Focus Group Participants

Methodology:

- Participation in this research project includes completing this consent form as well as attending a focus group session, which will occur in February 2001.
- You will be a participant in a focus group with other SRHB care providers to share your knowledge and experience of what cancer patient have told you regarding their experiences while navigating the NWT healthcare system, their experiences with living in a remote area and the challenges in accessing health care. and what patients have told you they feel would improve the system and our services.
- Your participation is voluntary and you may withdraw at any time without having to provide a reason and without affecting your employment at SRHB.
- You may refrain from answering or discussing any questions that you prefer not to discuss, or stop the interview at any time. You may also ask to have the tape recorder turned off at any time, or to request that your contributions to the group not be transcribed.
- Should you withdraw at any time all information which you have provided will be destroyed on your instructions.
- Only other participants in the focus group, the researcher and the project sponsor will know of your participation in this group. Outside of the focus group your participation will be kept confidential.
- You will not be identified by name throughout the research notes or final document. To maintain your anonymity in the documentation, you will be identified through out the research by a pseudonym.
- Participant consent forms will be kept for one year and then destroyed in accordance with the SRHB Ethics Policy.
- The focus group session will last approximately one and one half to two hours.
- This session will be audio taped and transcribed. All data collected will remain confidential and locked in a secure cabinet. Participant consent forms will be kept for one year and then destroyed in accordance with the SRHB Ethics Policy. All other data gathered will be destroyed immediately on completion of this project.
- There will be no monetary compensation to you for participating in this study. However, you may obtain a full report of the research results, free of charge, by completing the request section at the end of this consent form. The report will be ready in May 2001, at the earliest. In addition a copy of the final report will be housed at Royal Roads University and the library at Stanton Regional Hospital.
- The data from this research project may also be used in articles submitted to professional journals or presentation at health conferences. Again, the same standards of confidentiality and anonymity will be maintained.
- No deception will be used at any time in this study, and the researcher will endeavor to ensure that no harm of any kind will come as a result of your participation in this study.

Appendix B-3

Information and Consent Form – Focus Group Participants

Your signature indicates that you are satisfied with and fully understand the information regarding your participation in this research project and you agree to participate. By signing the consent form, you agree to have the results of this research presented at academic conferences and/or published in print or electronic form.

Please feel free to ask for clarification or new information throughout your participation in this study. If you have further questions concerning matters related to this research, please contact Ruth Robertson at (867) 669-4146 or 873-3240 evenings and weekends or by e-mail st8akaos@theedge.ca . If you have further questions concerning matters related to this research please contact Fred Jacques for verification of authenticity of this project at (403) 251-9608 or by e-mail fjacques@netcom.ca

Having read the preceding pages carefully please sign below if you give your consent to participate in this research project.

______________________________	____________________
Participant	Date
______________________________	____________________
Researcher	Date

Please initial to indicate you have received a copy of this consent form to keep for your records and reference_______

Request for a copy of the final report

If you would like a copy of the results, please complete this section.

Name: ______________________________

Address: ______________________________

Postal Code: ______________________________

Phone: ______________________________

Participant Interview Questions

The following information will assist in analyzing any significant trends in the responses.

Current Age: ____________________
Age at the time of Diagnosis: ____________________
Gender: ____________________
Ethnicity/Ancestry: ____________________
Home community/Population: ____________________

1. As someone living in a remote part of our country, what was it like for you to find out you had cancer? What made you first go to the nurse or the Doctor? Who did you first see? Can you tell me about your experience with the whole process?

2. How did you feel when you were first told you had cancer? Who was with you? How were you told? Did you receive enough information?

3. What/who supported you through the process of being diagnosed and treated for cancer? Who/what helped you ? How did you cope? Can you name any of the support group or places that cancer patients in the Western Arctic can go to for help/support?

4. Can you describe your what it was like for you to get from place to place to get the care and the help you needed? From your home community? Between SRHB Medical clinics and within Stanton Regional Hospital, Community agencies, Edmonton, transportation.

5. What are the most important things to you in relation to the services and the care that you receive?

6. Can you suggest two or three things that we could we have done at this clinic to make it better for you? In the hospital? Outside the hospital?

Anything Else?

Is there anything else you would like to tell me about this experience?

Focus Group Discussion Guide

1. Opening Remarks, Housekeeping issues.
2. Review Consent, Confidentiality.
3. Introduction to focus group process.
4. Questions before we begin?

Focus of this Session

The goal of this project is to learn about the experiences of patients living in a remote area of our country at an anxiety producing, emotionally charged period of their lives - finding out they have cancer. There may be additional anxiety placed on the patients as they live in a remote area where access and availability to services may be a challenge.

The purpose of this focus group is to find out from you as care givers, what cancer patients have shared with you regarding their experiences with being diagnosed with cancer while living in the NWT. The focus will be on the feedback you have received from cancer patients, not on what you as a care provider think the issues and challenges are for these patients.

It is anticipated that this information will assist in determining what factors would contribute to the effectiveness of services offered by Stanton Regional Health Board Medical Clinics to cancer patients living in the western arctic.

Appendix C-2

Focus Group Discussion Guide

Questions to Guide Discussions

1. Can you tell me what patients have said about being diagnosed with cancer while living in a remote part of our country?

Prompts
-in respect to where they lived, proximity to family, medical facilities, access to treatment, services and medical benefits

2. Can you describe what patients have said about their experiences with navigating the healthcare system? What were the challenges they faced? What information about getting through the system did they say they did not have that would have made it a better experience for them?

Prompts
- travel, trying to figure out who arranges what, who pays for what?
- Is the number of steps in the process and issue that is raised? (seeing nurse, gp, specialist in the north and repeating it in the south)

3. What do patients say supported them through the process of being diagnosed and treated for cancer? How did they cope? Who/what helped them to survive?

Prompts
- family, care provider, spirituality

4. Based on the personal values, traditions and beliefs of the culturally diverse population we serve, what have cancer patients told you are most important to them in relation to the services and the care that they receive?

Prompts
- Interpreters, escorts, traditional medicine, traditional foods etc.

5. What have patients said that care providers could do to make it a better experience for them?

6. What other feedback have you received from cancer patients regarding their experiences with navigating through the NWT healthcare system and the care they have received at Stanton Regional Hospital Medical Clinics?