

**Palliative Care and the Kivalliq Region of Nunavut:
Determinants of Programme Development and
Implementation**

Bruce Douglas Martin, BSc, MD, CCFP, FCFP

**A Thesis
Submitted to the Faculty of Graduate Studies
In Partial Fulfillment of the Requirements
For the Degree of
Master of Science**

**Department of Community Health Sciences
Faculty of Medicine
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Canada**

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by

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A Thesis/Practicum submitted to the Faculty of Graduate Studies of
The University of Manitoba

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Abstract

The Kivallik Region of Nunavut is characterized by a widespread and geographically remote population of principally Inuit ancestry. The health care system in Canada's newest Territory is characterized by comprehensive interdisciplinary community-based primary care that is undergoing change to increase the incorporation of traditional Inuit values, and to create more programmes within patients' home communities. The objective of this research was to gather information that could contribute to palliative care programme development in this challenging environment. The study used a mixed methods research approach. The quantitative realm consisted of three survey tools created for the study; the qualitative consisted principally of in-depth interviews. The study identified a substantial burden of illness from both neoplastic and chronic disease. The majority of patients reported to have received palliative care died in their home community; surviving relatives expressed comfort with both care and care providers. The health system is establishing the infrastructure for home care, but there are limited respite and other in-patient resources necessary for the continuum of end-of-life care. There are health human resource challenges both in numbers and educational attainment in palliative care, but providers expressed an interest in continuing their professional development. Key-informants contributed substantial information regarding Inuit cultural beliefs that could contribute to culturally sensitive end-of-life care. Recommendations were advanced based upon the study's findings.

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the 'big computer project' would ever end, and to Stefanie who with good fortune was oblivious. And most of all to Moni Fricke who deserves the greatest acknowledgement for her support, patience, and tolerance of my consuming much discretionary and family time to complete this work.

Thank you all.

Dedication

This thesis is dedicated with loving memory to my mother

Dorothy Lorraine Martin

1922-2001

who did not live to see this work completed.

She inspired me to learn, to write, and to comfort others.

She was fortunate to receive the comfort and support of family and other palliative care providers as Creutzfeldt-Jakob Disease stole her wit, her wisdom and her capacity to nurture.

Definitions

Inuktitut: language of the Inuit. Dialects, or variants of the language, tend to be similar to near neighbours, and divergent from those of more distant co-linguists (McFarlane & Clements, 1998; Fossett, 2001).

Inuit: the persons of indigenous ancestry of the eastern Canadian Arctic (Fossett, 2001).

Inuit Qaujimagatuqangit: Inuit knowledge, wisdom, values and beliefs.

Inuit Tapiriit Kanatami (ITK): the national Inuit organization in Canada, incorporated in 1972; also referred to as the Inuit Tapirisat of Canada (ITC).

Kivalliq Region: the southernmost administrative region of Nunavut. It is comprised of the five communities on the west coast of Hudson Bay, the inland community of Baker Lake, and Coral Harbour on Southampton Island. The community of Sanikiluaq of the Baffin Region (Qikiqtaaluk) has been included in the context of this document, as health services to this community are administered by the Kivalliq Region.

Mixed methods approach: a research methodology that incorporates both qualitative and quantitative strategies to data gathering and data analysis (Creswell, 2003).

Nunavummiut: the residents of Nunavut.

Palliative Care: the active total care of patients whose disease is not responsive to curative treatment (World Health Organization Expert Committee, 1990).

Qualitative study: an inductive, evolving methodologic design in which themes may emerge during data collection (Creswell, 2003).

Quantitative research: a deductive methodologic design with fixed and set research objectives (Creswell, 2003).

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Chapter 1. Introduction

There are significant challenges to the provision of end-of-life care within any health care system. Geographic remoteness and cross-cultural environments compound such challenges. The principle objective of this study was to gather and record knowledge that could contribute to the development and implementation of a sustainable palliative care programme to address the spiritual, cultural and end-of-life care needs for the residents of the Kivalliq Region of Nunavut. A mixed methodology research strategy was used to enrich quantitative data with narrative data from key-informants who were relatives of patients who had received palliative care, or providers of care. The study includes a review of the relevant literature and a summary of the organization and structure of the health care system that could support palliative care. The research results are summarized into topics that include the burden of illness and demographic patterns regarding the current provision of care, capacity considerations, and an exploration of cultural beliefs. Recommendations are advanced based upon the study's findings for consideration of the readership, and specifically for the Kivalliq communities and their leadership.

1.1 Palliative Care

The World Health Organization (WHO) has defined palliative care as:

...the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for

patients and their families, where family refers to either actual relatives or other key people important to the patient. Palliative care: affirms life and regards dying as a normal process; neither hastens nor postpones death; provides relief from pain and other distressing symptoms; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; and offers a support system to help the family cope during the patient's illness and in their own bereavement. (World Health Organization Expert Committee, 1990)

The Canadian Hospice Palliative Care Association has embraced similar concepts in its definition of palliative care (2002). The Inuit Tapiriit Kanatami, the national Inuit organization in Canada, has adopted the WHO definition because it is perceived to be in harmony with Inuit beliefs (Inuit Tapiriit Kanatami, 2002).

The WHO Expert Committee has stated that:

Programmes of palliative care stress that illness should not be regarded as an isolated aberration in physiology but considered in terms of the suffering that it causes and the impact that it has on patients' families. (World Health Organization Expert Committee, 1990)

This holistic approach has fostered acceptance of the understanding that the "unit of care" is the family, rather than the patient alone. Another fundamental WHO principle is that palliative care requires a team approach which recognizes the contribution that can be made by all health care workers.

This document will reflect these stated interpretations of palliative care and palliative care programmes.

1.2. Study Area

The Kivalliq Region is the southernmost of the three administrative regions of Nunavut. It is comprised of widely geographically dispersed Inuit hamlets including the five communities on the west coast of Hudson Bay, the inland community of Baker Lake, and Coral Harbour on Southampton Island. The community of Sanikiluaq of the Baffin Region (Qikiqtaaluk) has been included in the descriptive study because health services to this community are administered by the Kivalliq Region. A map identifying these communities is included as Appendix A. The population of each of the eight communities varies from approximately 300 to 2,200 as identified in Table 1; the total population of the study area is approximately 8,200 (Statistics Canada, 2003). Individuals of Inuit ancestry comprise approximately 90% of the community population, with the exception of Rankin Inlet. The Inuit culture is well preserved in these settings and the range of individuals for whom Inuktitut was the first language learned and still understood varies across communities from 79% in Rankin Inlet to 95% in Repulse Bay (Statistics Canada, 2003; Moffatt, O'Neil, & Young, 1990; Statistics Canada, 2002; Moffatt et al., 1990). The vast majority of residents identify themselves as Christian; Protestant adherents outnumber Catholics in the Region, and typically there is a dominant faith within each community.

There is a well-documented diversity of cultural and social features described at the time of European contact, with variable influences through the transition of social and cultural life during the last centuries. The historical cultural groups include the Aivilingmiut of Repulse Bay and southward to

Chesterfield Inlet, the Sallirmiut of Southampton Island, the Caribou of the west coast and Baker Lake, and the Qiqiktarmiut of the Belcher Islands (Damas, 1968). Accordingly, and despite the political-geographic grouping, it should not be assumed that there is a homogeneous culture of the Kivalliq Inuit.

Health initiatives of Nunavut integrate health and social services through a centrally governed system of the Department of Health and Social Services and administered regionally in Baffin, Kitikmeot, and Kivalliq. Care in the community is characterized by a comprehensive interdisciplinary primary care approach with an evolving home care programme. There is no programme specific to palliative care which is currently being provided within the primary care system with support from family members of patients. Emerging programmes of the Kivalliq Region have resulted not only from the communities' expressed needs and desire to reduce unnecessary dislocation from home, but also from the political ideology of progressive self-sufficiency as articulated in the Bathurst Mandate Pinasuaqtavut which is included in its entirety as Appendix B (Government of Nunavut, 2000). The development of a formal palliative care programme for the Kivalliq Nunavummiut should be in keeping with these tenets.

Table 1. Communities of the Study Area by Population, Ancestry, and First Language Based on 2001 Census.

Community	Number of inhabitants	Number and proportion of Aboriginal ancestry	Number and proportion with Aboriginal first language
Arviat	1899	1790 (94)	1750 (92)
Baker Lake	1507	1415 (94)	1065 (71)
Chesterfield Inlet	345	325 (94)	305 (88)
Coral Harbour	712	695 (98)	665 (93)
Rankin Inlet	2177	1720 (79)	1325 (61)
Repulse Bay	612	590 (96)	580 (95)
Sanikiluaq	684	645 (94)	645 (94)
Whale Cove	305	295 (97)	285 (93)
Total Study Area	8,241	7475 (91)	6620 (80)

Note: The study area includes the communities of the Keewatin (Kivalliq) Census Region and Sanikiluaq of the Baffin Census Region. This table constructed from 2001 census data identifies that 91% of the study population self-declare Aboriginal ancestry, the great majority of whom declared that the first language learned at home in childhood and still understood is an "Aboriginal Language" (Statistics Canada, 2003).

Chapter 2. Literature Review

The literature was initially reviewed to provide background information for the original research proposal. An electronic literature search was conducted using MEDLINE® with the subject headings of palliative care (all subheadings, and organization and administration), health services indigenous, ethnic groups, Indians North American, hospice care, and rural health services. Additional relevant references were obtained from the citations of the indexed literature. References were subsequently updated by specific search headings. Citations were catalogued using Reference Manager Professional Edition® Version 9.5 Copyright© 1984-2000 ISI ResearchSoft.

The following literature review does not present a comprehensive review of the palliative care literature but concentrates on specific publications relevant to end-of-life care in remote areas and cross-cultural environments.

2.1 Organization of Palliative Care

The World Health Organization (WHO) has provided a schema for comprehensive palliative care programmes that include home care, consultation service, day care, inpatient care and bereavement support (World Health Organization Expert Committee, 1990). The WHO Expert Committee also recognized that such an organizational structure is not essential for good palliative care, given that palliative care is a “concept”. It was recommended that the service configuration of programmes in historically challenging communities

might best be developed with a community-based approach using the collective perspectives of patients and families, along with their health providers (O'Neill & Marconi, 2001).

There is acceptance of the longstanding tenet that home-care is an integral part of well-planned palliative care (Bowling, 1983). A prospective study that followed the course of illness among patients with terminal cancer receiving home-care service concluded that sufficient care could be provided at home (Hinton, 1994b). There was however an increasing preference for admission over time, and the study stated that home-care often needs complementing by in-patient care, and the availability of hospice beds permitted more confident perseverance at home (Hinton, 1994a). This study supported the earlier WHO Expert Committee premise that ideal home care requires a continuum of care between home and hospital. The Commission on the Future of Health Care in Canada specifically recommended that palliative home care services be provided to support people in their last six months of life, and advocated for expansion of the Canada Health Act to include home care (Romanow, 2002). The Commission also identified the important role of informal care providers in providing assistance at critical times; this was reflected by the priority recommendation that proposals for support programmes be generated by Human Resource Development Canada in conjunction with Health Canada (Romanow, 2002).

2.2 Determination of Need

The determination of need for palliative care programming is multifaceted and includes the influence of demography and pattern of illness as well as a population's perspective on the perceived dichotomy between curative and palliative approaches to care. A global perspective engaging the impact of demography, and specific implications of longevity is provided by Seale (Seale, 2000). Seale's work is reviewed here at length given the relevance to this study. He identifies an overall worldwide trend of longer life and the ageing of the population. The consequences are noted to be the experience of dying and the experience of bereavement. The consequences for the source of care for the dying are outlined, and 'developed' versus 'developing' countries display differences in response to needs of the dying. The expertise of hospice and palliative care is purported by Seale to have evolved from the lengthening of 'dying trajectories' as the cause of death shifted from infectious disease to degenerative disease. It is also stated that the care of dying people was impacted by a 1950's and 1960's paradigm of readiness to question scientific and professional authority, and assert individual autonomy. In that era there was institutionalization and medicalization of care with emphasis on curative efforts at the expense of palliative care. Seale attributes the emergence of hospice movements in some developed nations to have been a result of these factors, and the emergence of palliative care also occurred within a broad cultural context that included a tendency to plan for and control major life events. Cultural determinants of end-of-life care are paramount and by no means universal to all

developed nations. The challenges of providing palliative care in developing nations, despite need, were stated to include scarce resources and a balance between prevention and cure, or hospital and community-based care.

A recent review of mortality in the Kivalliq Region spanning the decade 1987-1996 revealed a continuing change in the pattern of cause-specific mortality among the Canadian Inuit wherein infectious disease is being progressively replaced by cancer and chronic disease as the principle contributors to death (Macaulay, 2002). A statistically concerning rate ratio existed for carcinoma lung and other cancers. Respiratory disease among adult women accounted for the second greatest proportion of deaths from known causes.

The most compelling determinant of need may be the desire to repatriate end-of-life care from secondary and tertiary centres to an individual's home community. The rationale may be sensed as a simple response to expressed desires of patients and families. The reason for such desires mandates special attention. It has been stated that:

Culturally sensitive support for dying and grieving Native patients and families may require that individuals and communities assert their prerogative to die in their homes and local communities. (Kaufert & O'Neil, 1995, p. 74)

This has been stated in the context of the fundamentally irreconcilable differences in understanding between the biomedical culture of health professionals and health institutions, and the Aboriginal cultural understanding of viability, death and grieving.

2.3 Cultural Construct of Death and Dying

Fulfillment of the WHO holistic concept of palliative care creates the need for an understanding of the beliefs within a culture concerning death and dying. The rationale is well articulated with reference to the cross-cultural setting in the following excerpt from an introduction to cultural issues in palliative care:

Those who have settled in a society where there is a dominant faith or culture other than their own increasingly adopt that dominant culture in many ways. However, they retain, almost deliberately to emphasize differences, their different practices at times of birth, marriage and death. (Neuberger, 1998, p. 777)

The essential requirements for effective cross-cultural palliative care practice in the Australian Aborigine experience has been articulated to include a triad of adaptation of practice to suit the patient's needs (Fried, 2000). The triad includes: wishes and life situation; the use of Aboriginal language interpreters, cultural brokers and community liaison workers; and working through and with existing Aboriginal service providers.

Determining personal choice surrounding end-of-life care has been identified as assisting the care provider in becoming aware of the patient's preference within a culture (Neuberger, 1998, p. 778). This approach acknowledges that there is considerable personal variation in the behaviour of groups and individuals within a culture. Neuberger further states that taking the time to inquire about personal preference may result in empowerment of the patient as at that moment the patient assumes a position of control, as he or she has information that the carer does not have.

Unfortunately there is very little in the medical or palliative care literature to assist care providers with an understanding of cultural beliefs concerning death and dying for Indigenous peoples. While there is a literature regarding Indigenous Australians and to a limited degree Canadian First Nations, it would be inappropriate to generalize these writings to the Inuit culture (Dunn, 2001; Prior, 2001; Hotson, Macdonald, & Martin, 1999). There are no indexed references in the medical literature describing Inuit cultural beliefs in the context of end-of-life care. However, in a treatise on the Inuit of the Central Arctic there are details regarding the ancient Inuit ideology of existence (Fossett, 2001). In Inuit cosmology, before conversion to Christianity, living creatures were invested with souls, which resided for all eternity in the name. Souls were immortal, and capable of infinite reincarnation into new physical bodies. Hence death was of little importance, as the soul-name would only be temporarily withdrawn from a physical body to be brought together at a later time by the union of a new physical body and an old soul-name.

2.4 Spirituality and Palliative Care

The spiritual dimension of palliative care is integral to the WHO concept of palliative care, and hence is essential to the discussion of programme development. The WHO Expert Committee offered the following definition:

“Spiritual” refers to those aspects of human life relating to experiences that transcend sensory phenomena. (World Health Organization Expert Committee, 1990, p. 50)

The Canadian Hospice Palliative Care Association defines spirituality as:

An existential construct inclusive of all the ways in which a person makes meaning and organizes his/her sense of self around a personal set of beliefs, values and relationships. (Ferris et al., 2002)

Both organizations identify that the involvement of the patient in a community of faith and practice may or may not be a component of the individual's spiritual dimension of life.

An early contribution to the cancer care literature in the context of spirituality is from Vastyan in which he defined and interpreted spirituality from his own Christian context (Vastyan, 1986). Spirituality was defined as "participation in spiritual life", as involving a surrendering of our natural tendency to strive for control. Spirituality involves the capability to accept rather than control life situations. Four elements of a spiritual experience were stated by Vastyan: confrontation and finitude, submission, transcendence, and cherishing. It is stated that beyond the psychological reaction to a diagnosis of cancer there is a ubiquitous spiritual phenomenon of profound personal crisis. Vastyan asserted that caregivers should anticipate a patient's reaction to include a spiritual response and those responses should be recognized as such, and not simply dismissed as emotional events. Attending to a spiritual response is identified as an essential component of comprehensive care, and should not remain solely in the "purview of the hospital chaplain".

2.5 Palliative Care for Minority Population Groups

There is a limited Canadian literature regarding care for minority population groups, hence this review summarizes contributions from international sources. Minority patients, including American Indians in the United States, have been identified as less likely to receive health services and care across the spectrum of disease when compared with white patients controlling for multiple confounders (Geiger, 2001). Explanations for differences in access to care among minority patients included impairment of physician-patient communication, and lack of cultural sensitivity and cultural competence of health care providers (Geiger, 2001). Underutilization of palliative care by African Americans, although not explored in depth, has been identified as potentially related to the barriers that the poor and disenfranchised have traditionally encountered, and not solely related to the lack of universal health care insurance (Gibson, 2001). The same author identified as a concern the under-representation of minority health professionals in palliative care faculty development and other education and training programmes. In the United Kingdom it was sensed that patients from minority ethnic groups were under-represented in hospice settings (Gaffin, Hill, & Penso, 1996). Two recommendations were forthcoming from that study. Firstly, culturally sensitive services were recommended to meet an anticipated increase in the need for palliative care for people from minority communities. Secondly, it was recommended that an 'ethnic monitoring' system be created to assess engagement of minority populations in the full range of palliative services offered.

Upon further review by other authors the under-representation was thought to be due to an epidemiologic phenomena reflecting different patterns of illness that would result in differing needs for palliative care, but factors including referral patterns of primary health care teams were recommended for future study (Fountain, 1999). A current review does not identify literature citing disparities in access to palliative care in Canada by minority population groups.

2.6 Provision of Palliative Care for Indigenous Populations

There are generally limited references to the provision of palliative care for indigenous populations. An exception is the comparatively extensive literature documenting palliative care needs and service utilization experience among the Australian Aboriginal population (Palliative Care Australia, 2001; Fried, 2000). Fried identified barriers to accessing palliative care services among Aboriginal patients. These barriers included poor penetration of palliative care services into remote and rural areas, culturally inappropriate services for Aboriginal people, and poor access to existing services reflecting an integration of patients' own health care choices and Aboriginal patient's invisibility to service providers. It was specifically noted that nonmalignant terminal conditions may not have lead to referral for palliative care. The burden of serious illness and increased mortality rate was viewed as contributing to an over-representation of Aboriginal people in a specific palliative care practice. Issues regarding the needs of care providers were also identified. It was noted that non-Aboriginal practitioners

working in remote and cross-cultural care situations may need management guidance, debriefing and additional practical and emotional support.

There is a substantial literature regarding the pivotal role of Aboriginal interpreters in urban hospitals (Kaufert et al., 1995; Kaufert, Putsch, & Lavallee, 1999). The literature speaks to their role as mediators between dying and grieving patients, family members and clinical staff in urban environments. The cultural conflicts were identified as multifactorial, but included differences in approaches to truth-telling in the sharing of bad news, contrasts in biomedical and cultural understanding of causation, and approaches to treatment that span technologic intervention and traditional healing practices. The Canadian literature also includes approaches to examining cultural differences in ethical care by clinicians in their provision of care to Aboriginal peoples in both a general sense, but also in a case-study specific application to palliative care (Ellerby, McKenzie, McKay, Garipey, & Kaufert, 2000).

There is no indexed literature describing palliative care in the circumpolar Inuit. It is specifically worthy of note that comprehensive reviews of health status of the circumpolar Inuit and models of health care delivery to the Canadian Inuit do not make reference to palliative care (Bjerregaard & Young, 1998; Archibald & Grey, 2000). However, palliative care in select First Nations has been studied; this research identifies not only issues of geographic isolation and administrative planning, but also the need to accept and respect the decisions made by the patient, family and community (Hotson et al., 1999).

2.7 Education for Care Providers

Education has been identified as a priority for the effective implementation of a palliative care programme (World Health Organization Expert Committee, 1990). Education needs have been categorized in three dimensions: incorporation of indigenous attitudes, beliefs and values; knowledge base; and skills. The WHO Expert Committee recommended strategies that would include palliative care knowledge transfer that would include health care providers, patients and families, and the public. It was suggested that palliative care be included as compulsory in courses leading to a basic professional qualification.

There is an extensive and relevant literature specific to rural and cross-cultural environments. The literature cites education initiatives for palliative care in rural areas (Freeman, Ramanathan, Aitken, Dunn, & Aird, 1998; Elsey & McIntyre, 1996), cultural influences in care by providers (House, 1993), patient education with cultural considerations (Juarez, Ferrell, & Borneman, 1999), education for family members as care providers in rural settings (Wilkes, White, & O'Riordan, 2000), and education to enhance cross-cultural interaction (McNamara, Martin, Waddell, & Yuen, 1997).

Chapter 3. Study Objective, Ethical Considerations and Methodology

3.1 Study Objective

The ultimate objective of this study was to gather and record foundational knowledge that could contribute broadly to the development and implementation of a palliative care programme in the Kivalliq Region of Nunavut. The study was designed to achieve this objective in the following dimensions:

- 1) Survey the literature regarding palliative care and palliative care programming with specific emphasis on cross-cultural and remote settings;
- 2) To conduct a health system review to determine current policy and programme supports that could contribute to the development and sustainability of a palliative care programme in the Kivalliq Region;
- 3) Identify the need for palliative care in the Kivalliq Region from a demographic perspective and identify the broad determinants of a sustainable programme;
- 4) Identify Canadian Inuit beliefs on death and dying by reviewing existing literature, and supplement this with information from key-informants;
- 5) Approach providers of care and relatives of patients who had received palliative care to gain their perspective on the historical provision of palliative care and initiatives that could support continued programming.

3.2 Ethical Considerations

The framework for ethical protection of individuals and communities involved in this research was consistent with contemporary approaches to research with indigenous peoples. Specifically, the study adhered to the principles articulated by the Inuit Tapirisat and subsequently published jointly by the Nunavummi Qaujisactulirijikkut (Nunavut Research Institute) and the Inuit Tapirisat of Canada and are identified in the following paragraph (Nunavut Research Institute & Inuit Tapirisat of Canada, 1998; Inuit Tapirisat of Canada, 1996).

A community information sheet was made available in English and Inuktitut and the former is provided as Appendix C. Written informed consent was obtained from all individuals who participated in the survey questionnaire and/or in-depth interviews; the participant information and interview consent form is provided as Appendix D. The process of negotiating informed consent included describing comprehensive details of the study including potential benefits and risks of participation, guaranteeing confidentiality and anonymity, assuring the right to withdraw from participation without compromising the relationship to the researcher or health programmes, and ensuring the right to access research results. The anonymity of the home community of key-informants was also assured. Efforts were made to identify and respect traditional knowledge with specific reference to cultural and spiritual approaches to death and dying, and bereavement.

Community members were identified to assist with recruitment of key-informants, to distribute survey questionnaires and to be interpreters for in-depth interviews. Dissemination of the completed study was to be widespread to include the Kivalliq Inuit Association and the Department of Health and Social Services, Kivalliq Region. Presentations were offered to Kivalliq communities and the report was to be made available in non-technical language and with translation to Inuktitut. The final report and an English and Inuktitut executive summary were to be provided to the Nunavummi Qaujisaqtulirijikkut (Nunavut Research Institute) to ensure maximum accessibility of the research results to Nunavut residents, being a condition of the research licence.

The ethical issues in palliative care research have been discussed in the literature, and were taken into consideration in formulation of the research methodology for this study. de Raeye has presented a self-admittedly provocative stance that no research methodology can be said to be benign. She questions the validity of the consent process and the capacity of research ethics committees, and challenges the justification for research in the palliative care client group (de Raeye, 1994). The stance is refuted by Canadian palliative care directors and they not only defend a quarter century of international palliative care research progress, but assert the need to proceed ethically to:

...continue to ask questions, check our observations, test our interventions, strive for further improvement in therapy, and join those who are ill in asking questions about the nature of their suffering. (Mount, Cohen, MacDonald, Bruera, & Dudgeon, 1995)

Acknowledging the concern of the impact of interviewing bereaved survivors cited by de Raeve, the informed consent protocol in both survey questionnaire participants and in-depth interview key-informants included notification of the potential risk to participants and extended an offer of support should an emotional response occur to the nature of the questioning. Because the methodological framework of this study included only brief in-depth interviews and not an ethnographic approach conducted over time, the decision was made to interview surviving relatives who were directly involved in providing support to patients. Patients currently receiving end-of-life care were not interviewed. It should be noted that research in palliative care has been deemed essential by the Inuit Tapiriit Kanatami, with research focused on topics that include traditional belief and expectations around death and dying, development of a culturally appropriate model, and evaluation of service delivery (Inuit Tapiriit Kanatami, 2002).

Ethics approval was obtained from the Health Research Ethics Board of the Bannatyne Campus Research Ethics Board, University of Manitoba prior to commencing the study. A Science Research Licence was issued by the Nunavummi Qaujisaqtulirijikkut (Nunavut Research Institute) under the Nunavut Scientists Act and is reproduced as Appendix E.

3.3 Methodology

3.3.1 Research Design Overview

The research design for this study utilizes a mixed method approach to achieving the stated objectives. This approach to research is widely used in both the social and clinical sciences and has been increasingly advocated as a procedure for conducting research (Creswell, 2003, p. 208). The value of mixed methodology in the palliative care literature has been reported to include the validation of quantitative results (Strang, 2000). Differing approaches to exploring specific components of palliative care is additionally endorsed in the following statement:

Qualitative research, relatively new to biomedicine, has opened new avenues of study that are especially applicable to palliative medicine, where many of the most interesting and challenging phenomena do not lend themselves to quantitative analysis. (Mount & Seely, 1999)

The research approach of this study specifically reflects the concurrent triangulation strategy by typology. The approach was adopted in an effort to confirm, substantiate and cross-validate findings from each of the approaches to data collection. It was recognized that the inherent weaknesses of one method may offset the strengths of the other. The concurrent approach involving simultaneous collection of quantitative and qualitative data during a single visit to a community required less time than a sequential approach. There was by intent no greater priority given to the qualitative or quantitative component of the data. While it was anticipated that the quantitative data may be of significant interest to health care administrators, especially in the realm of establishing need and

identifying the pragmatics for a sustainable programme, the in-depth interviews were postulated to contribute a perspective specific and sensitive to the needs of patients and families, and providers of care in the Kivalliq Region. The integration of data was viewed as having occurred throughout the process of the research. Data was integrated in the interpretation phase by comparing information that was obtained by both methods. In keeping with the concurrent mixed method approach, the reporting of qualitative and quantitative data and the analysis and interpretation has been combined by themes wherein the data from each source is identified as convergent or divergent.

The research approach was guided by accepted mixed methodology approaches as summarized in the literature (Creswell, 2003 Chapter 11). A visual model of the strategy identifying the quantitative and qualitative components of the study is provided in Figure 1. The components of the study are specifically described in the following sections.

3.3.2 Qualitative Component

The qualitative components of the mixed methods procedure of research in this study consisted principally of in-depth interviews of key-informants. This data was additionally supplemented by open-ended questions in a survey tool designed to gather data from health care providers in the study area.

The purpose of a qualitative approach in this study has been previously identified, and principally was selected to obtain descriptive data relevant to

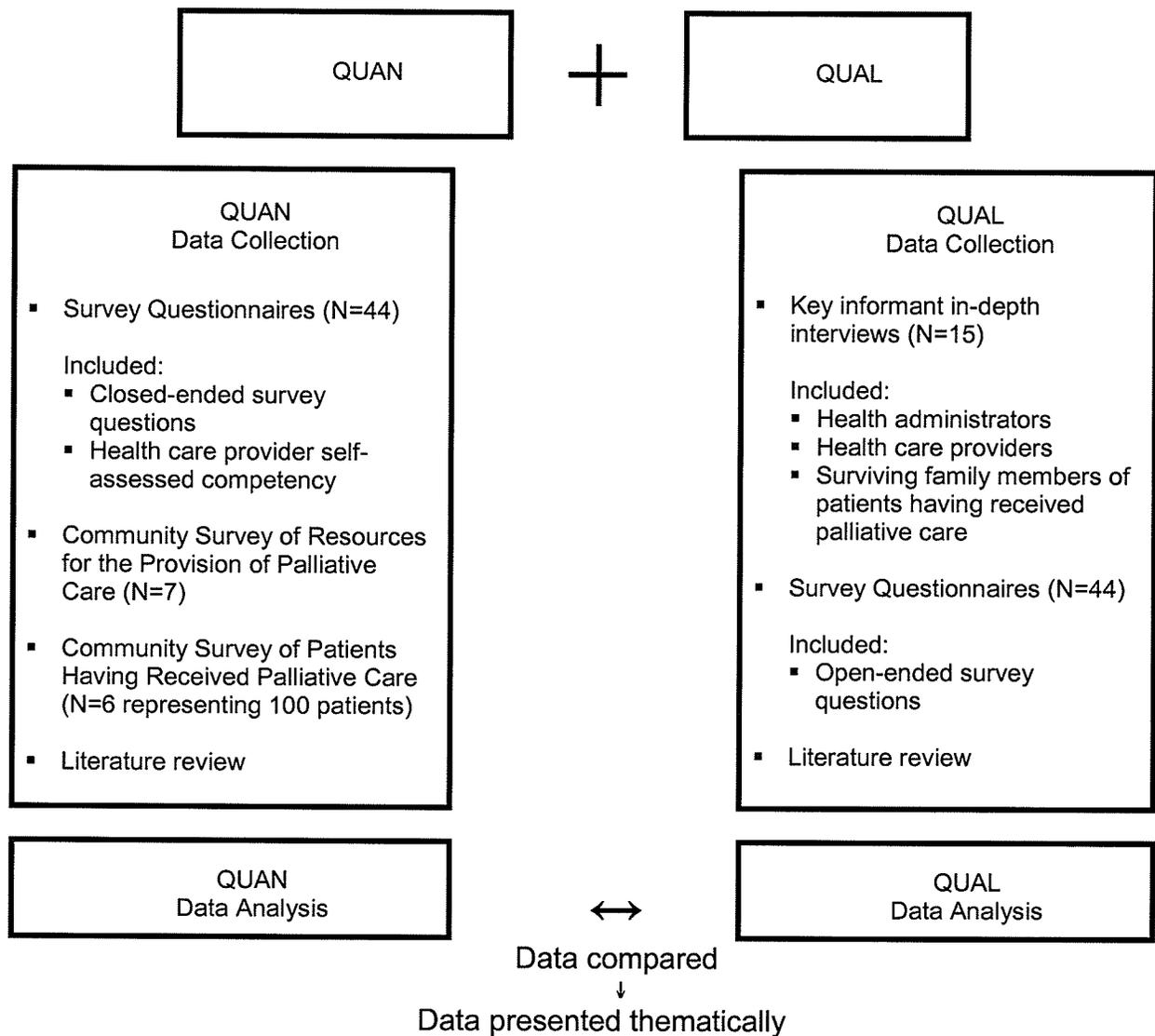


Figure 1. A Visual Model of the Mixed Methods Approach in This Study.

Note: The study manifests the concurrent triangulation strategy typology of mixed methods research. “QUAN” and “QUAL” stand for quantitative and qualitative respectively, and the same number of letters indicates equality between the data forms. The “+” indicates concurrent data collection. The individual components of this study and corresponding numbers are identified under their respective quantitative or qualitative category. Adapted from Creswell, 2003, p. 214.

palliative care based on the experiences and knowledge of the key-informants. The strategy does not adhere strictly to any one of the five specific traditions of inquiry identified by Creswell (Creswell, 2003). The strategy most closely approaches the *case study* method as individuals in this research participated in in-depth interviews to explore their personal experiences. The strategy should not be identified as *ethnographic* despite the study area specifically involving the Inuit of the Kivalliq Region; the study can neither be viewed as being conducted over a prolonged period of time, nor primarily observational, both criteria being requisite to the ethnographic strategy (Creswell, 2003). The research was conducted exclusively by the study author and this was acknowledged as a potential contributor to study bias. The researcher was well known to the health care providers and healthcare administrators of the study area, and as a former physician practitioner in the study area could have been known to community members who were surviving members of patients who had received palliative care. The researcher was not only known to have been involved in programme development but was also known to have the potential to influence future programme initiatives in the study area. The researcher was additionally known to have personal interests in the provision of palliative care.

This component of the study was formally introduced by the researcher in a teleconference that included nurse managers and healthcare administrators in five of the eight communities of the study area; the remaining three communities were unable to participate due to telecommunication difficulties or unexpected clinical urgencies at the time of the teleconference. Those communities were

contacted at a later date. Nurse managers were asked to identify potential key-informants for the study; these were to be surviving relatives who were directly involved in the care of a patient who received palliative care. Once identified, the nurse manager was to approach the individual to explain the research initiative and determine their willingness to meet with the researcher and become a key-informant to the research. Potential health care providers as key-informants were recruited in a similar fashion, with an effort not only to identify individuals who represented the diversity of health care providers in the Kivalliq Region but also to ensure they had current and active involvement in palliative care. Health care administrators were approached by the researcher on the basis of their position within the health care system. A total of 15 key-informants participated; the categorization of the roles and relevant attributes of each key-informant are identified in Table 2. It should be noted that two key-informants had dual roles and thus may have contributed data in more than one realm.

This component of the research was conducted in June 2003. Three sites were purposefully selected for interviewing key-informants. One community was the centre of administrative governance for the study area, and therefore facilitated meeting with healthcare administrators. The other two communities were identified by the researcher as there were clusters of potential key-informants in each community. Additionally the communities were known to represent historically distinct cultural groups, which afforded the opportunity for potentially different data. The researcher had not been involved in direct care provision in any of the three communities for eight years.

A participant information and consent form was created for this study and was approved by the Health Research Ethics Board of the Bannatyne Campus Research Ethics Board, University of Manitoba and Nunavummi Qaujisaqtulirijikkut (Nunavut Research Institute). The consent form was available in both English and Inuktitut; the former is available as Appendix D. All participants provided informed consent. Anonymity of the key-informants was assured, as were references to his or her home community, patients, or care-providers. Interviews were conducted in the key-informant's location of choice within the community; ordinarily this was the Health Centre or other place of work; one interview was conducted in the key-informant's home to honour his choice. Interpreters were available to all Inuit key-informants regardless of the English fluency of participants. Individuals who were surviving relatives of patients who had received palliative care were offered the opportunity of having a support person present in addition to the interpreter. An open-ended, semi-structured in-depth interview format was used with all key-informants. Interviews were guided by a 'theme list' specific to the role of the informant role; see Appendix F. Interviews were audio recorded. Field notes were entered onto a tracking document that allowed for demographic data, descriptive notes and reflective notes; see Appendix G. The audio-recordings were transcribed into Microsoft® Word 2002 Copyright © Microsoft Corporation 1983-2001. Where an interpreter was used, only the interpreter's English translation to the researcher was transcribed. The audio recordings were erased after the transcripts were reviewed and cross-checked for accuracy.

Data analysis began with assembling the transcribed data and accompanying field notes specific to each key-informant and collating them by category of key-informant. All transcripts were read initially, and then specific ones were selected for detailed review in order to identify a list of topics. The transcripts were then reviewed and segments of each were coded based on the list of topics. Portions of transcripts were copied and grouped by theme. Transcripts were reviewed intermittently based upon observations from other data including the quantitative components of this study. Analysis was not aided by the use of qualitative data analysis software.

An approach to verification of the data is adapted from Creswell (Creswell, 2003; Creswell, 1994). Validity in the context of qualitative research assumes a different dimension than the quantitative concepts of internal validity (reliability) and external validity (generalizability) (Creswell, 1994). The qualitative approach embraces the concept of whether or not the findings are accurate and focuses not so much on generalizability as it does the uniqueness of the findings specific to the context of the study (Creswell, 2003, Creswell, 1994). In this study triangulation of data from different sources was the main approach to validation of the findings; convergence was sought between individual key-informants as the research progresses as well as reflection on findings of the quantitative domain. 'Member-checking', a procedural method suggested by Creswell was not undertaken, but discussion was undertaken with interpreters in two community settings to gain their comment on the researcher's interpretation of

findings from key-informants, particularly those who were surviving relatives of patients who had received palliative care.

Distinct from the qualitative data from key-informant interviews was the data obtained from open-ended questions in survey questionnaires. The Survey Questionnaire participants were given the opportunity to provide opinions on potential barriers to increasing community-based palliative care; to recommend changes to the Health Centre or the administration of services, and lastly to provide any other comments. Information was entered into a database to facilitate analysis (Microsoft® Access 2002 Copyright© Microsoft Corporation 1992-2001). All comments were reviewed initially, and thereafter identified then grouped by topic, while retaining identifying information of the informant. This data was integrated with qualitative data from the key-informant interviews.

The qualitative data was integrated with the quantitative data and information from reviews of the literature and the health system. The interpretation of the data was purposefully integrated thematically in the following chapters that individually identify information central to palliative care in the Kivalliq Region.

3.3.3 Quantitative Component

The quantitative components of the mixed methods procedure of research in this study consisted principally of three survey tools that were developed specifically for this research study. The survey tools included: a survey

Table 2. Key Informants to the Study

Health Administrators:

Position	No. of Informants	Years in current position
Home and community care coordinator	1	1.5
Nurse manager; large community	1	1
Nurse manager; small community ^a	1	12

Health Care Providers:

Profession	No. of Informants	Years in current position
Clergy ^b	2	>20; 13
Community Health Representative	1	8
Home and community care worker	2	2
Interpreter	1	>10
Registered nurse ^a	1	12

Surviving relatives of patients having received palliative care:

Relationship to patient(s)	Principle diagnosis(es)	Time since care
Daughter	Cancer lung	11 years
Daughter	Cancer lung and COPD*	~10 years
Daughter	Cancer liver	3 months
Daughter (both parents)	Cancer (both patients)	8 and 9 years
Husband ^b	Cancer; primary unknown	20 years
Son	COPD*	1 year
Wife	Cancer lung	2 years

Note: The 15 key-informants to the study have been categorized as follows: health care administrators, health care providers, and surviving relatives of patients having received palliative care. The paired superscripts (a) and (b) identify informants who had dual roles and contributed in both identified categories. *COPD denotes chronic obstructive pulmonary disease.

questionnaire of health providers, a survey of resources in Kivalliq Region communities to support palliative care, and a survey of patients who had received palliative care in the Kivalliq Region. The development and use of each data collection tool will be described in the following sections.

3.3.3.1 Survey Questionnaire

A questionnaire was specifically developed for this study to survey health care providers of the Kivalliq Region and obtain information specific to the provision of palliative care. The survey tool is provided as Appendix H and in later discussion it will be referred to as "Survey Questionnaire" to distinguish it from other survey instruments developed for this study. A survey was chosen to allow a larger sampling of health care providers than what could have been achieved through key-informant or focus group interviews. The survey was cross-sectional with the data having been collected over a span of two months in the study area. The survey tool consisted of information and consent statement and a self-administered questionnaire that included 23 questions including open-ended and closed questions, and graded responses on a Likert-like scale. Participants were asked to identify their profession and duration of time spent in their current position and in remote communities. The survey explored clinical experience with end-of-life care, formal training in palliative care, self-assessed competency in aspects of care provision, perceptions regarding location of care, and awareness of culturally determined beliefs regarding death, dying and bereavement. Three open-ended questions gave participants the opportunity to

provide opinions on potential barriers to increasing community-based palliative care; to recommend changes to the Health Centre or the administration of services, and to provide any other comments.

The questionnaire format was modified from a 50-question administered survey that was developed to comprehensively evaluate the provision of palliative care in First Nations settings (Hotson et al., 1999). That existing instrument did not have established validity or demonstrated reliability. No other survey instruments were identified in the literature with specific reference to remote or cross-cultural settings.

A key contact person was identified in seven of the eight communities of the study area to assist in distribution of questionnaires. The key contact was instructed by the researcher regarding identification of potential participants by describing the target sample group; the intent was to distribute questionnaires to all health care providers within the community. The number of questionnaires provided for distribution to each community was based on existent human resource estimates during the study period; the number of questionnaires actually distributed was not known.

The questionnaires were distributed over the two month period of June and July 2003. Participation was anonymous. The questionnaires were returned individually by the participants to the researcher in self-addressed, stamped envelopes, secure facsimile transmission or air courier. 44 questionnaires were returned. The self-declared professional designation of respondents is identified in Table 3; two individuals indicated dual professional designation. The response

Table 3. Survey Questionnaire Respondents by Self-declared Profession.

Clerk Interpreter	6	Registered Nurse, DHSS, H&CC	3
Community Health Representative	4	Registered Nurse, DHSS Public Health	0
Community Mental Health Worker	0	Registered Nurse, Agency	1
Health/Social Services Administrator	0	Registered Psychiatric Nurse	1
Home Care Aide	7	Rehabilitation Occupational Therapist	0
Member of the clergy	1	Rehabilitation Physical Therapist	0
Physician, full-time	1	Social Worker	2
Physician, <i>locum tenens</i>	2	Other: medical students(2) hospice attendant (1)	3
Registered Nurse, DHSS, full time	12		
Registered Nurse, DHSS, relief	3		

Note: Participants were asked to self-identify their position as “health provider” using the above noted categories. There were 44 individual respondents. Two indicated dual professional designation: Clerk interpreter/Community Health Representative and Community Health Representative/Home Care Aide; this clarification accounts for the total of respondents in this table to be 46.

Note: “DHSS” refers to the Department of Health and Social Services of the Nunavut Government; “H&CC” refers to the Department of Health and Social Services Home and Community Care Program; “Agency” refers to a private corporation contracted by the Nunavut Department of Health and Social Services to provide locum nurses.

rate of questionnaire recipients is not known as the key contacts responsible for distribution did not have to account for the number of questionnaires distributed. Similarly the total number of potential participants and their individual professional designations are not known, although approximate numbers can be determined from the survey tool designed to assess community resources. However, the majority of health providers by designation in the Kivalliq Region were represented by survey questionnaire responses. Follow-up contact with the key contacts was done to encourage responses, but since participation was anonymous, compliance with requests could not be determined.

Quantitative data and narrative responses to open-ended questions were entered into a database to facilitate data analysis (Microsoft® Access 2002 Copyright© Microsoft Corporation 1992-2001). Numerical data from self-assessed competencies in the provision of palliative care was analyzed statistically with calculation of arithmetic means and standard deviations, and comparison between data was done using paired t-tests with calculated p values.

Participation by communities of the study area for this and other surveys is summarized in Table 4.

3.3.3.2 Community Survey of Resources for the Provision of Palliative Care

A survey tool was developed specifically for this study to evaluate community resources that could support the provision of palliative care in the Kivalliq Region. The survey was formally entitled “Community Survey of Resources for the Provision of Palliative Care” and is included as Appendix I; in

later discussion it will be referred to as “Survey of Community Resources” to distinguish it from other data collection tools developed for this study. The survey included components specific to health human resources, other community-based human resources, facility resources and materiel resources specific to the needs of palliative care patients. The survey tool was developed by the researcher in general consultation with community health care providers; the component on materiel resources was further modified with input from a palliative care consultant (Garcia, 2003). The survey was sent to a key contact in each of the eight communities of the study area in June and July 2003. All eight communities in the study area responded. Survey data was collated manually.

Participation by communities of the study area for this and other surveys is summarized in Table 4.

3.3.3.3 Community Survey of Patients Having Received Palliative Care

A survey tool was developed specifically for this study to obtain information regarding residents of the Kivalliq Region patients who had received palliative care in their home community. The survey was formally entitled “Community Survey of Patients Having Received Palliative Care” and is included as Appendix J; in later discussion it will be referred to as “Survey of Patients Having Received Palliative Care” to distinguish it from other sources of data that may be discussed in this document. Categories of information included patient age and sex, diagnosis, duration of palliative care by actual time period or subjective impression, year of death and place of death. Specific instructions

were provided for interpretation of each category of data. Additionally palliative care was defined in the context of the study as “the active total care of patients whose disease is not responsive to curative treatment”; the intent of this was to clearly state to the survey respondent which patients should be identified.

Respondents were advised to seek information from community health care providers if additional information was required. It should be noted that each community Health Centre maintains a mortality logbook that identifies the deaths of all residents of the community, regardless of cause or location of death.

Written instructions to survey respondents did not specifically advise reference to this document, but subsequent discussion with informants confirmed that the community mortality logbook was used as a reference. Retrospective data was requested for five to ten year’s experience. It was requested that patient names not be included on the data collection form.

Review of the literature did not identify a survey tool of this nature. The validity and reliability of this survey tool is unknown. It should be specifically noted that the study did not include a process of validation to confirm that patients identified by survey respondents had in fact received care that could be confirmed to be palliative care.

The nurse managers from all communities were invited to participate in this component of the study. Information was provided from six of the eight communities; the population of those six communities represented 55% of the total study area population. All participating communities submitted data from 1993 to 2003; some community data included 1992. 100 patients were identified

as having received palliative care in the period of time reported and all data was recorded for analysis. It was recognized that there may be incomplete data for 1992, and data was available for only a portion of the study year 2003. Results were entered into a database to facilitate data analysis (Microsoft® Access 2002 Copyright© Microsoft Corporation 1992-2001). For purposes of data analysis, duration of care was grouped as short, medium, or long duration interpreted as less than 3 months, 3 to 6 months, and more than 6 months of care respectively.

Participation by communities of the study area for this survey, and the number of patients reported from the respective communities is shown in Table 4.

Table 4. Community Participation by Survey Type.

Community	Survey		
	Survey Questionnaire	Survey of Community Resources	Survey of Patients Having Received Palliative Care (N = number of patients)
Arviat		√	√(35)
Baker Lake	√	√	
Chesterfield Inlet	√	√	√(10)
Coral Harbour	√	√	√(16)
Rankin Inlet	√	√	
Repulse Bay	√	√	√(14)
Sanikiluaq	√	√	√(20)
Whale Cove	√	√	√ (5)

Note: Three surveys were distributed for this study: Survey Questionnaires, Survey of Community Resources, and Survey of Patients Having Received Palliative Care. Community response by survey type is identified; the number of patients identified in the latter survey is noted.

3.3.4 Literature Review

The literature review was facilitated by an electronic literature search using MEDLINE[®] to search the subject headings of palliative care (all subheadings, and organization and administration), health services indigenous, ethnic groups, Indians North American, hospice care, and rural health services. References were updated using the Cubby[®] option of Pub Med[®]. Additional references were obtained from the citations of the indexed literature, and on recommendation of colleagues and key-informants. Citations were catalogued using Reference Manager Professional Edition[®] Version 9.5 Copyright[®] 1984-2000 ISI ResearchSoft.

3.3.5 Health System Review

A review was undertaken of the current health and social services system as it related to palliative care. Current documents pertaining to health services for Nunavut were examined with specific reference to existing initiatives that could influence the provision of palliative care in the Kivalliq Region. Other documents identified in a general environmental scan of national initiatives influencing palliative care were obtained and reviewed. This data was supplemented with in-depth semi-structured interviews of health providers and health administrators as key-informants to obtain a greater understanding of current initiatives and operational issues specific to the Kivalliq Region.

3.4 Dissemination of Results

In addition to the academic review process and oral presentation, the investigator is committed to provide information from this study to the communities and leadership organizations. The process of dissemination of results has been previously discussed in the context of ethical considerations. This study will be deemed to be complete when the results of the research are returned to the communities of the Kivalliq Region, the Kivalliq Health Centres, the Nunavut Department of Health and Social Services administrative staff, and the Kivalliq Inuit Association. Broader dissemination through publication, conference presentation and distribution to requesting organizations would be considered in consultation with stakeholders.

Chapter 4. The Organization and Structure of the Health Care System and the Supports to the Provision of Palliative Care in the Kivalliq Region

4.1 Overview

A review of the health and social service system that could support the development of palliative care in the Kivalliq Region has been undertaken using government documents and publications, other resources, and key-informant interviews. This chapter will consider the system in three parameters: the Nunavut Health and Social Services system, extra-territorial supports to the Kivalliq Region Health and Social services programmes, and the emerging environment that may influence palliative care for residents of the Kivalliq Region.

4.2 Nunavut Health and Social Services

4.2.1 Territorial System

The following is a summary of documents of the Department of Health and Social Services, and in particular a review of relevant components of the Departmental Business Plan of 2003-2004 (Department of Health and Social Services, 2003).

The Department of Health and Social Services has the responsibility for a broad range of programmes and services: primary and acute health care, child protection and family services, mental health, health promotion and protection,

and injury prevention. These programmes are directed by the following Mission Statement:

To promote, protect and provide for the health and well-being of all Nunavummiut, incorporating Inuit Qaujimajatuqangit [Inuit knowledge, wisdom, values and beliefs] at all levels of service delivery and design.

and Vision Statement:

The well-being of all Nunavummiut will be enhanced by individuals leading productive lives in self-reliant and healthy communities throughout the territory.

Among the Department's Guiding Principles relevant to the development of palliative care programmes are cultural sensitivity, continuum of care, and sustainability. Similarly, relevant Departmental values include service, respect, and Inuit Qaujimajatuqangit.

An environmental scan reported in the Business Plan 2003-2004 has identified a number of concerns pertinent to this research. It is observed that there are significant cultural and linguistic challenges including a need to adapt an older style of western governance and service delivery to one that is culturally appropriate to the majority Inuit population. Demographic change is also noted as a significant determinant as there is an ever-increasing elderly population and therefore an inherent need for new services and programmes that previously did not exist. Additionally there is a need to repatriate services within Nunavut to reduce the social and economic disruptions caused by travel. Lastly, note is made of the need to review the healthcare system in light of the Bathurst

Mandate to ensure accessibility, effectiveness, responsiveness and sustainability. The Bathurst Mandate is reproduced in Appendix B.

The core business programmes of the Department of Health and Social Services include: Directorate, Population Health, Social Services, Health Protection, Care and Treatment, and Health Insurance. The Care and Treatment programme mandate includes in-patient and outpatient services, public health, and chronic care and home care service delivery. The objectives of Care and Treatment include the delivery of culturally sensitive programmes and services in an integrated and coordinated fashion, establishing respite services in every Nunavut community, and providing care to clients who have lost the ability to care for themselves, including those requiring palliative care. A stated priority of 2003-2004 is to improve the integration of services among health staff with Social Service and Mental Health Staff. Home Care and Continuing Care is a specific programme of Care and Treatment, with a specific mandate to enable Nunavummiut to avoid facility-based care and to live at home to maximize control over their own lives. The Nunavut Home and Community Care programme is supplemented by the First Nations and Inuit Home and Community Care Program, a federally funded initiative (Health Canada, 1999). The First Nations and Inuit Home and Community Care Program has broadly stated purposes but specifically makes no mention of palliative care. The stated contributions of Inuit are equally broad and include all aspects of programme development and implementation, as those responsibilities are not assumed by Health Canada.

There is a telehealth network in Nunavut, Ikajuruti Inungnik Ungasiktumi (IIU) which has a stated goal of improving accessibility and quality of health care for Nunavummiut; the network has also been used for continuing professional development of health professionals. IIU serves fifteen communities, five of which are in the Kivalliq Region. The network development was funded in part by Health Canada through the Canada Health Infostructure Partnership Program (Government of Nunavut Communications, 2003).

It should be noted that the services that may contribute to collaborative palliative care activities are administered by different business programmes of the Department of Health and Social Services; mental health services are governed by Population Health; Adult Support Services including social worker activities are within Social Services; Information Technology and Telehealth are within the Directorate.

There are three regions within Nunavut: Baffin, Kitikmeot and Kivalliq. There are health service variations within each region but programme direction is Departmental. Each Region has an administrative infrastructure.

4.2.2. Kivalliq Region Health and Social Services

The Kivalliq Region is the southernmost administrative region of Nunavut and is comprised of seven Inuit Hamlets. Health and Social Services are responsible additionally for administering programmes to the community of Sanikiluaq of the Baffin Region. The Kivalliq model of care is based upon an integration of primary health care service providers working in the eight

community health centres, while receiving support from resident physicians in Rankin Inlet, and itinerant physicians and other health professionals elsewhere. In-patient acute care is not provided currently within the Region, and accordingly patients must be transferred to hospital facilities in Manitoba with resultant dislocation from cultural and linguistic supports and often-prolonged separation from family. Emerging programmes, including comprehensive rehabilitation services have resulted not only from the communities' expressed desires to reduce unnecessary dislocation from home, but also from the political ideology of progressive self-sufficiency as articulated in the Bathurst Mandate Pinasuaqtavut (Government of Nunavut, 2000). Self-sufficiency in health includes the creation and sustaining of improved community resources. A Health Centre with limited in-patient resources is under construction in Rankin Inlet with an anticipated completion date of 2004.

Special mention should be made of the three facilities that provide residential care within the Kivalliq Region. All three operate under contract to the Department of Health and Social Services. Arviat has an Elder's Centre that provides principally care for older individuals who need support in activities of daily living; residents from other communities are welcome for long term or respite care. Nursing services are offered as an extension of the Arviat Health Centre as required. Palliative care has been provided in that facility. The Baker Lake Hospice Association is contracted to provide a variety of services including home and community care that includes palliative care activities. The Hospice Association also administers the Martha Talirug Centre which is a group living

environment with residential facilities for seniors and a dedicated palliative care room. Chesterfield Inlet has a long-term care facility for disabled children, and has attended to the needs of children with neurodegenerative disorders; the facility has not provided care historically for adults on an acute need or respite basis.

Four programme areas report to the position of Executive Director, Kivalliq Region Department of Health and Social Services: acute care and public health, home and community care, mental health, and social services.

Home and Community Care was established as a formal programme in 2002 following a needs assessment and development of a programme design. The programme is now coordinated regionally by an administrative nurse director. Palliative care is within the mandate of the programme. The complement of staff is variable depending upon community size and depending upon recruitment and retention of staff. Homemakers and home and community care workers are co-trained for personal care. Home care nurses are the team leaders and client case coordinators.

The Regional Home and Community Care Manager and a Health Centre nurse manager were key-informants for this study. Both stated that provision of palliative care was a personal as well as programme priority. The historical scenario prior to the development of Home and Community Care was identified where acute care priorities for the regional health centres would often displace the need for home based care. Care specific to palliative care patients was typically fragmented between community-based providers, and frequently lacked

a formal case-management approach. The impact of fragmentation was worsened by the range of approaches of individual community physicians and perpetuated by absence of clinical practice guidelines and patient specific care plans. The potential for collaborative and interdisciplinary care is viewed as exciting and timely. Identified challenges include the integration of disciplines, timely case conferencing, communication of clinical information necessary for care, and 'acquiring' a designated palliative care consultant for clinical support. Volunteerism was identified as a barrier to programming in some communities. The Home and Community Care manager was interested in exploring the interface between the volunteer paradigm and the home and community care providers; the potential positive outcome was the strengthening of the "sense of community". A statement by one key-informant, and collaborated by the other was as follows:

As long as supports are there, and supports are provided, it is rare that institutional level of care can't be provided at home. In-home respite care ...home based respite ... can be provided '24/7'.

It was identified that regional resources in Baker Lake and Arviat may have potential for the infrequent circumstance where facility care is necessary prior to the opening of the regional facility in Rankin Inlet.

4.3 Extra-Territorial Supports to the Kivalliq Region Health and Social Services Programmes

The secondary care facility for the Kivalliq Region is in Churchill, Manitoba. The historically high clinical activities of the facility, including mental

health and social services programmes, have diminished as the community-based infrastructure has developed in the Kivalliq. Physicians in Churchill historically provided clinical services to the Kivalliq, but since 1997 physician resources in the Region have been patriated to the Inuit communities thereby effectively diminishing the direct contact between Churchill physicians and the Nunavummiut. Primary care clinical supports are still provided by Churchill clinicians by telephone consultation for communities that do not have a resident or itinerant physician available.

Medical specialist, rehabilitation and information resource supports for community-based care, education and programme support are coordinated by the University of Manitoba J. A. Hildes Northern Medical Unit as contracted by the Department of Health and Social Services. Palliative care has been neither identified nor requested as a component of the contracted resource supports. Tertiary care inpatient and outpatient care and diagnostic services are located in Winnipeg as administered by the Winnipeg Regional Health Authority (WRHA). There are no resources of the WRHA dedicated to the residents of the Kivalliq, and specifically no designated palliative care resources. The Nunavut Department of Health and Social Services administers the Kivalliq Inuit Services which coordinates patient care for Nunavummiut in liaison with resources of Winnipeg, Churchill and the health centres of the Kivalliq Region. The programme also coordinates interpreter services for Inuit patients receiving care in the Winnipeg region. A boarding home is located in Winnipeg and is contracted to provide supports to patients who require medical care in Winnipeg,

and their escorts. Nursing services if required at the boarding home are contracted with private agencies, and are not integrated with home care nursing resources of the WRHA.

4.4 Emerging Environment in Palliative Care

There is an apparent emerging environment in palliative care that may be timely in supporting initiatives in the Kivalliq Region. The first three documents reviewed below have similar recommendations that could create ideological momentum for palliative care programme development in Nunavut. The fourth document may be instrumental in providing programme structure within the Kivalliq Region.

The Subcommittee to Update *Of Life and Death* of the Standing Senate Committee on Social Affairs, Science and Technology, as chaired by Senator Carstairs has published a final report that has made a number of significant recommendations (Carstairs & Beaudoin, 2000). These include the development of a national strategy for end-of-life care; development of comprehensive and mandatory health professional training in end-of-life care, and enhancement of communication between the public and the health care community; a national research strategy including better measures of rural and urban differences in the delivery of end-of-life care; development of broadly accepted guideline and standard development; and emphasis on advance directives in the planning and communication of patients' wishes. A list of recommendations was provided to achieve the recommendations. On a more sobering note, it is stated in the

Senate Report that progress in implementing the unanimous recommendations of the 1995 *Of Life and Death* Report was evolving too slowly. The following remark is made:

Inadequate federal and provincial collaboration, deficient allocation of resources, and insufficient attention to the end-of-life health care needs of Canadians were some of the contributing factors. (p. 3)

Additionally, it should be noted that there were no submissions from, or specific references to Nunavut in the Subcommittee Report. There is nothing in the Report that identifies why there are no initiatives specific to Nunavut which appears surprising given the challenges pursuant to the creation of the Territory only one year prior to the Senate Subcommittee Report.

The Commission on the Future of Health Care in Canada was released in November 2002 (Romanow, 2002). The Commission recommended expansion of the Canada Health Act to include home care; it is unclear how this will interface with existing initiatives in Nunavut subsequent to the First Nations and Inuit Home and Community Care Program. The Commission specifically recommended palliative home care services to support people in their last six months of life. The important role of informal care providers in providing assistance at critical times is reflected by the priority recommendation that proposals for support programmes be generated by Human Resource Development Canada in conjunction with Health Canada. The Commission recommendations reiterate recommendations of the above-noted Senate report.

The Inuit Tapiriit Kanatami (ITK) released a document entitled "Discussion Paper on End-of-life and Palliative Care in 2002" (Inuit Tapiriit Kanatami, 2002).

Recommendations are made based upon information gathered from the different Inuit regions. It is specifically noted that Nunavut did not respond to the questionnaire regarding palliative care, but it is stated that:

...the similarity of answers from one region to another, allows us to state that the situation of Palliative Care in this region [Nunavut] is similar to the others. (p. 15)

The recommendations include access to, and coordination of services, education and training, respect of Inuit culture, support to care givers, and research. The focus of the report may reflect a specific interest in development of initiatives, given that an earlier review by ITK of health care models in Inuit regions did not identify palliative care as a service or programme for Canadian Inuit (Archibald et al., 2000).

In 2002 the Canadian Hospice Palliative Care Association released "A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice" (Ferris et al., 2002). This document presents a standardized approach to hospice palliative care that is representative of a national consensus-based model for a consistent approach to patient and family care, organizational development, education and advocacy. The proposed model is quite comprehensive and would serve well as a framework for a Kivalliq Region palliative care programme.

Chapter 5. Burden of Illness and the Demographic Patterns Regarding the Provision of Palliative Care

5.1 Overview

A principle determinant of the need for and subsequent design of a palliative care programme would be the patterns of life-limiting illness in the population. The study has considered this determinant specifically for the Kivalliq Nunavummiut in the following broad categories: cause of death, illness trajectory, age patterns and location of death. The results and discussion incorporate information from both the quantitative and qualitative data. A principle data source was the Survey of Patients Having Received Palliative Care; data was provided by six communities of the study area and included 100 patients who died between 1992 and 2003. The survey tool was previously described in Chapter 3; it should again be noted that the provision of palliative care to patients reported in this survey was not confirmed by retrospective review or other process of data validation. Conclusions could therefore be considered *a priori*. This does not imply that care was not provided, but rather that the designation of care as palliative care must be interpreted in light of the perceptions of the informants and the milieu of their comprehensive primary care practice environment in the Kivalliq Region.

5.2 Cause of Death

The cause of death for patients having received palliative care in the Kivalliq Region will be identified from differing sources and perspectives. The data from the Survey of Patients Having Received Palliative Care will be presented. This will be followed by a review of the perceptions of health care providers who have provided palliative care in remote community settings as determined by data from the Survey Questionnaire. Lastly, data from a mortality study conducted in the Kivalliq Region will be provided (Macaulay, 2002).

The principal diagnosis of patients reported to having received palliative care was lung cancer, followed closely by all other cancers, respiratory disease, mixed circulatory-respiratory illness, and circulatory disease; other diagnoses were uncommonly reported and included neurodegenerative disorders. This data is presented in Figure 2. Summarized by diagnostic category, 59% had a principal diagnosis of cancer and 41% had a non-cancer diagnosis, as displayed in Figure 3.

Survey Questionnaires explored the experience of health providers with the provision of palliative care during their clinical involvement in remote communities. Respondents were asked to identify the primary diagnosis for patients for whom they had provided palliative care. They were also asked to select what other diagnoses contributed to the need for palliative care; a list was provided for respondents to choose from. The format of the questionnaire did not exclude provision of care to patients from remote communities other than those of the study area. All 44 respondents identified cancer as the principal diagnosis;

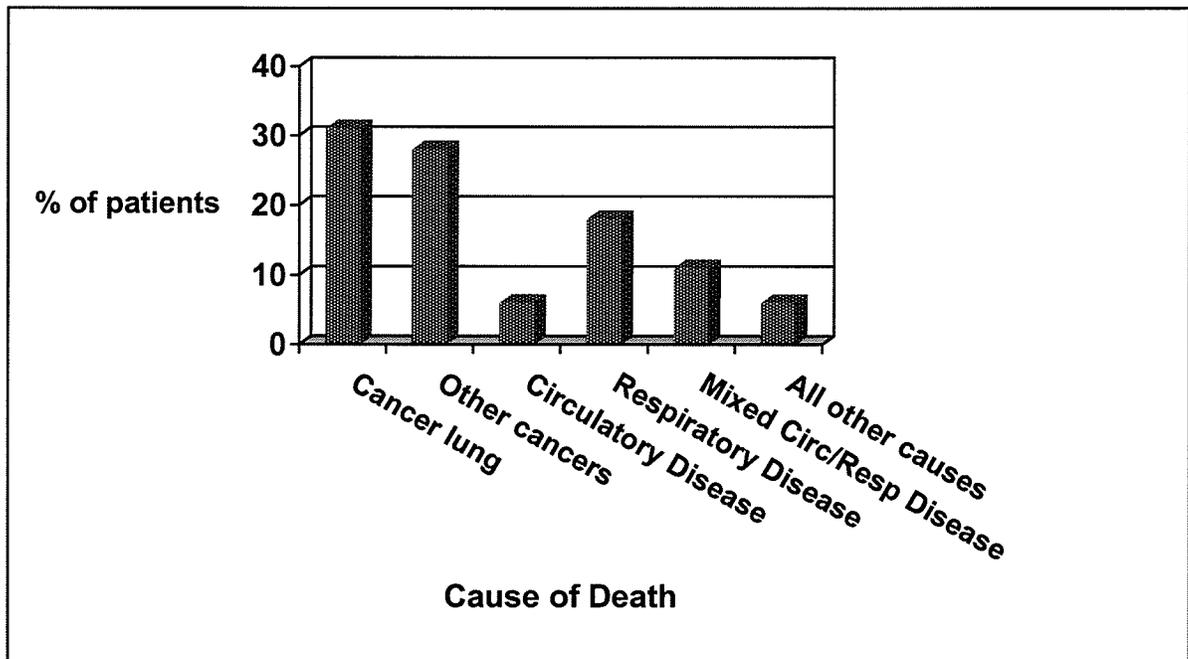


Figure 2. Cause of Death by Diagnostic Category for Patients who Received Care; Kivalliq Region, 1992-2003.

Note: The diagnosis contributing to death for patients reported to having received palliative care in the Kivalliq Region is identified by percentage of deaths. Note is made of the dominance of cancer, particularly lung cancer, and respiratory disease. This data is derived from the Survey of Patients Having Received Palliative Care and is based upon 100 patients from six of the eight communities of the study area, and spans the time period of 1992-2003.

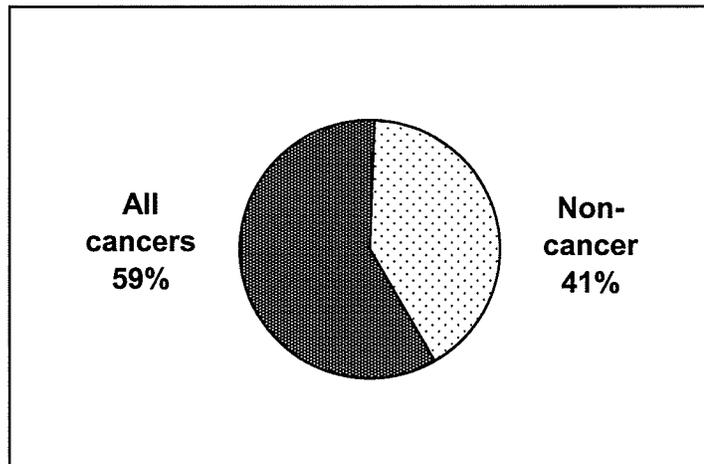


Figure 3. Categorization of Cause of Death, Cancer versus Non-Cancer; Kivalliq Region, 1992-2003.

Note: Cancer is the dominant cause of death in patients reported to having received palliative care in the Kivalliq Region; non-cancer deaths were predominantly due to respiratory and circulatory diseases. The data is based upon the Survey of Patients Having Received Palliative Care submitted by six of the eight communities of the study area including 100 patients and spans the time period of 1992-2003.

the frequency of response to other diagnoses in decreasing order is as follows: respiratory disease (44%), circulatory disease (24%), renal failure (16%), cerebrovascular disease (14%), and HIV/AIDS (2%). No other diagnoses were identified. This data is displayed in Figure 4.

The mortality patterns in the Kivalliq Region of Nunavut have been previously reported for the decade of 1987-1996 (Macaulay, 2002); the document not only identifies the leading causes of death, but also provides comparative death rates with Canada as a whole. The major causes of cancer death were lung, colon and other gastrointestinal cancers, and nasopharyngeal cancer; main causes of circulatory death were stroke, congestive heart failure and ischemic heart disease; adult respiratory deaths were mainly due to chronic obstructive lung disease. Comparison of death rates to Canada as a whole revealed significantly elevated rate ratios of 4.1 for lung cancer and 2.7 for respiratory disease, although death rates from circulatory disease were not dissimilar. This data is presented in Figure 5. These stark differences in cause of death from Canada as a whole give cause for concern regarding the transferability of palliative care programming from other jurisdictions of Canada to the Kivalliq Region. The pattern of cancer of the lung and respiratory disease as dominant causes of death may influence the human resource and other programme infrastructure necessary to address the symptom profile and duration of illness that may characterize these two diseases.

The striking similarities between causes of death of patients reported to having received palliative care and the data of the Kivalliq Region mortality study

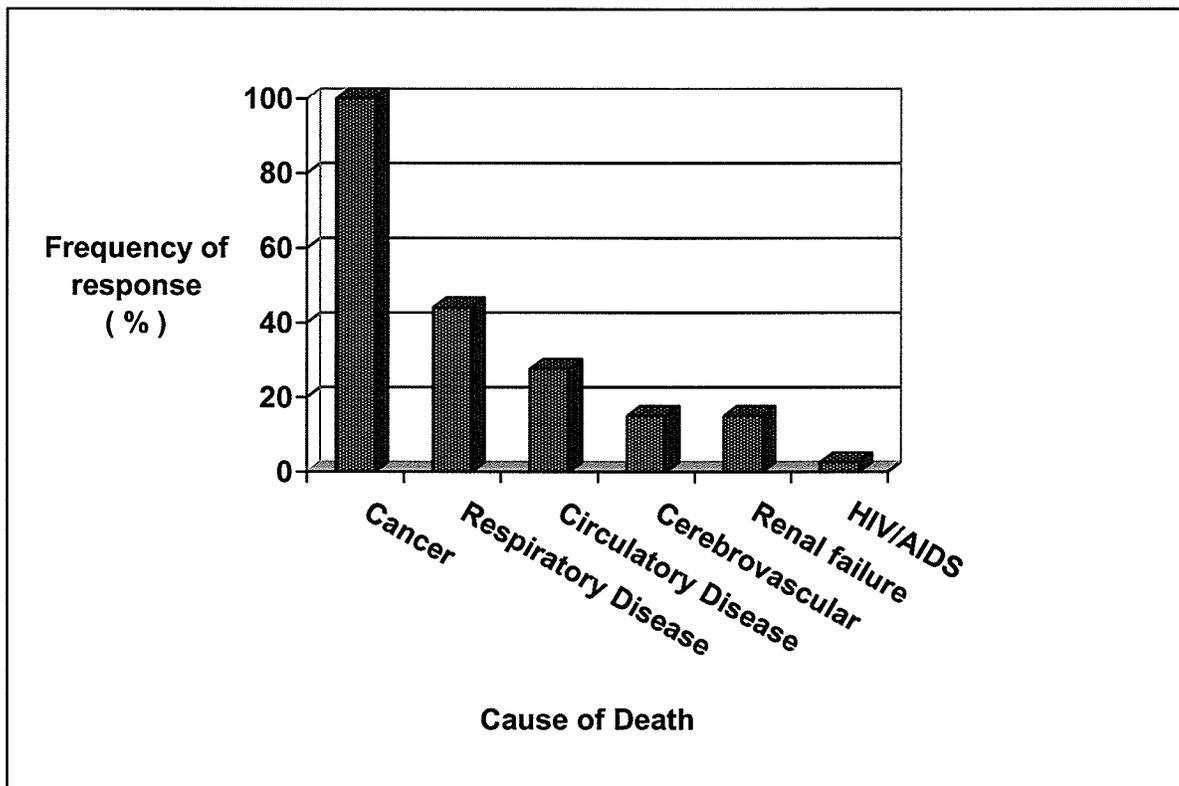


Figure 4. Principle Diagnosis, and Other Diagnoses of Patients to Whom Kivalliq Region Health Providers Reported Providing Care.

Note: This data is derived from the Survey Questionnaire in which health providers were asked to identify the principal diagnosis of patients to whom they had provided care, and identify other diagnoses. The frequency of response to each question is reported from 44 survey respondents. 100% of respondents identified cancer as the principal diagnosis. The frequency with which respondents identified other diagnoses is presented by percentage frequency of response; the dominant response was respiratory disease.

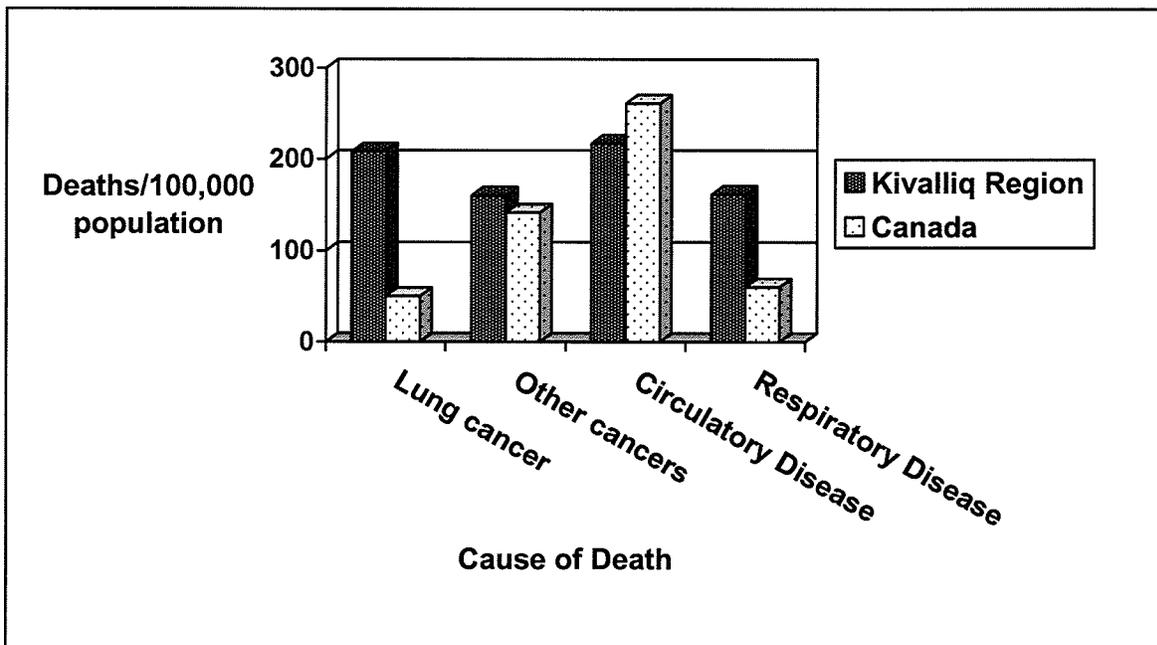


Figure 5. Age Standardized Annual Mortality Rates from Natural Cause; Kivalliq Region 1987-1996 and Canada.

Note: This figure summarizes the age standardized annual mortality rates in the Kivalliq Region from a previous study spanning the decade 1987-1996 (Macaulay, 2002).

Note: The elevated rate ratios for lung cancer (4.1) and respiratory disease (2.7) in the Kivalliq Region compared to Canada as a whole may create potential palliative care programme differences when compared to existent programmes elsewhere in Canada. There are similar patterns of mortality from circulatory disease in the Kivalliq Region compared to Canada.

are worthy of comment. It would appear that patterns of mortality are predictive of the patterns of diagnoses for patients being provided palliative care, and thus this crude population data is useful in determining the need for programme supports on a Regional basis. The data would also strongly suggest that there are no barriers to the provision of palliative care on the basis of diagnosis. This conclusion is supported by the perception of healthcare providers who have provided their perceptions of the diagnoses that have contributed to their individual participation in the provision of care. All of this information suggests that in the Kivalliq Region there is acknowledgement of the inclusiveness of patients who need palliative care as identified by the WHO, being "...the active total care of patients whose disease is not responsive to curative treatment." (World Health Organization Expert Committee, 1990). The mandate of care provision to the Nunavummiut of the Kivalliq Region may already have been expanded beyond addressing solely neoplastic disease. This should be regarded as particularly reassuring not only to healthcare administrators but also to patients and their families given the contribution of respiratory disease to the pattern of mortality in the Kivalliq Region.

The foregoing data reflects patterns of diagnoses associated with the provision of care. The methodology of this study did not allow conclusive determination that all patients requiring care actually received care. Furthermore, there was no audit to compare the nature of end-of-life care with the reporting of care having been provided. If future studies validate the broad access to palliative care that has been determined by this study, there could be

confirmation that barriers to palliative care existent for other indigenous populations, particularly for non-neoplastic disease, have been overcome in the Kivalliq Region. Access to palliative care in this study is potentially in positive contrast to the experience of rural Aborigines in Australia, where it has been stated that palliative care services have poor penetration into remote and rural areas, and an observation that nonmalignant terminal conditions may not lead to referral for palliative care (Fried, 2000). The reported provision of palliative care within the Kivalliq Region is perhaps a tribute to the model of the primary health care system wherein it is unlikely that the nurse clinicians would be unaware of an individual's diagnosis or supportive care needs. Access to resources if not identified by the patient, or known to the nurse manager, would likely surface as a result of advocacy for care by a member of the direct or extended family.

Key informants were able to offer some perspectives. In the case of a home and community care worker, the following is offered about community knowledge of patients who are ill, albeit as a preface to a discussion regarding care at home:

Interviewer: Are there things that could be done to make palliative care even better at home? Like what things would make it better?

Home and Community Care Provider: Like, in the community you would know everything fast like, if somebody is dying, the community knows that that person is dying.

And the following is the response when a community nurse was asked about her knowledge of patients in the community for which she was responsible:

Community nurse: I have one pneumonectomy in town, cancer, and he's doing excellent, like I said, you go out on the land

and enjoy, he's a hunter, so he's great. He's feeling great. He goes out hunting.

Interviewer: So you have other patients that you know of in the community that you can expect will be moving into palliative care.

Community nurse: By the looks of them right now they are doing so good, I can look like 2 years down the road.

Interviewer: Right, but by diagnosis.

Community nurse: That's right.

Interviewer: You would postulate that the need will continue.

Community nurse: That's right. Another one had a lobectomy.

Interviewer: For cancer as well.

Community nurse: Yes. And he's doing fine too. Don't carve I said.

Interviewer: Don't carve.

Community nurse: Yes, he's got COPD as well.

Interviewer: Oh ok.

Community nurse: But the aim is to make use of the health they have right now to the best of their ability, they are hunters, they go hunt, and we do monthly checks to make sure their blood pressures are fine, they are not anemic, and so the home care nurse could help us with these chronically ill patients.

Interviewer: Right, in terms of surveillance at home.

Community nurse: That's right. Before they get to end stage.

Interpreter: And when they are hunters, it's best for them to be out on the land for a few days and when they are back they feel much better.

5.3 Illness Trajectory

It has been identified that the shift from infectious to degenerative diseases as the principle causes of death involves a prolonged duration of symptoms for terminal illnesses (Seale, 2000). It is further postulated by Seale that the capacity to predict death at an early stage of some illnesses led to the emergence of the category of 'terminal illness' and thereafter to the development of expertise reflected in hospice and palliative care. Accordingly, exploring and understanding the concept of symptom duration may be useful in programme

development and sustainability in the Kivalliq Region. The term “trajectory” is useful to describe the course of illness as it reflects a process occurring through time rather than a static process. The approach has been described in the disability literature (Kaufert & Kaufert, 1984) and more recently adapted in a visual model by the Canadian Hospice Palliative Care Association of Canada (Ferris et al., 2002); it is reproduced as Figure 6. In the model the top line represents the total quantity of concurrent therapy; the dashed line represents the distinction between curative and palliative management, but allowing a mix of therapeutic approaches based upon the patients’ goals for care and treatment priorities and options. The model facilitates consideration of both duration of illness and intensity of symptoms as contributors not only to the nature of programmes to address palliative care, but also individual case management within a programme structure.

The duration of palliative care support care provided to Kivalliq patients was assessed by the Survey of Patients Having Received Palliative Care. Nurse managers were asked to identify patients by age, sex, diagnosis, duration of care, year of death and place of death. Six of the eight communities were able to provide data summarizing 100 patients. Duration of care provision was reported quantitatively in months, or qualitatively as short, medium or long duration, interpreted as up to two months of care, three to six months of care or over six months of care respectively. Results of this data are presented in Figure 7 for

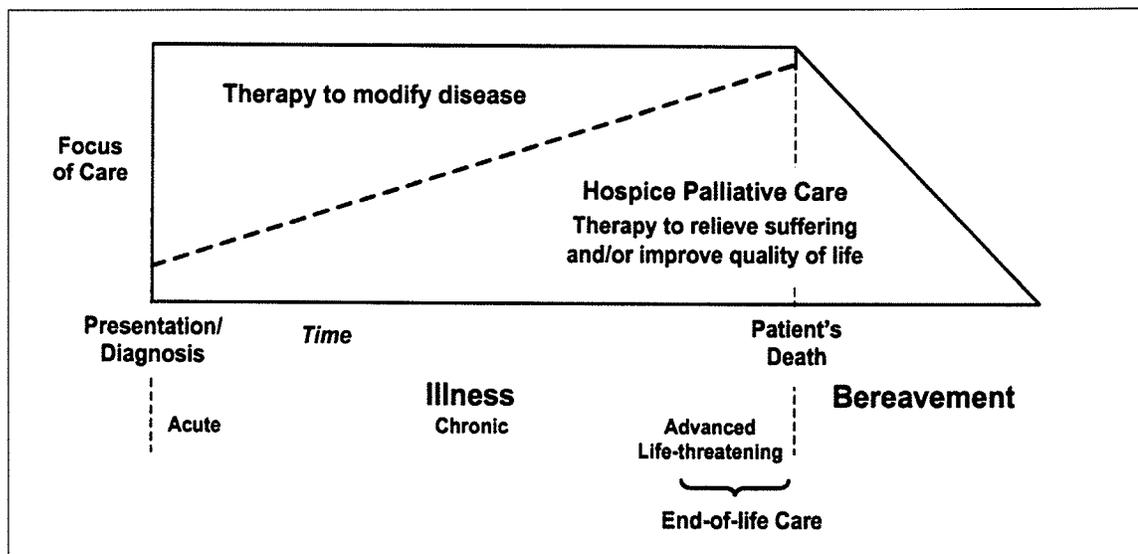


Figure 6. A Model to Guide Therapeutic Goals in the Course of an Illness.

Note: This visual model is an aid to determining the therapeutic goals during the course of illness from presentation or diagnosis through to the patient's death and subsequent bereavement of family and providers. In this model the top line represents the total quantity of concurrent therapy; the dashed line represents the distinction between curative and palliative management. The goals for care and treatment are shown to shift in focus from therapy to modify disease to therapy to relieve suffering and improve quality of life as the illness progresses from presentation to death. Adapted from Ferris et al., 2002, p. 18.

specific categories of illness, and in Figure 8 for cancer, non-cancer diagnoses and all diagnoses. It should be noted that no single category of diagnosis confers a specific pattern of disease trajectory, perhaps with the exception of the few cases of circulatory disease for which there was a short period of palliative care. Within any diagnostic group there is ordinarily a range of duration of care provision. It should be noted that the “all cancer” versus “non-cancer” categories display very similar patterns, with identical needs for long periods of palliative care; approximately 40% of all individuals received care for more than six months. These findings are in contradistinction to the literature that suggests that the illness trajectory is more prolonged in degenerative disease (Seale, 2000). In considering this data for programme development it is essential that duration of care not become a defining criterion of eligibility for palliative care.

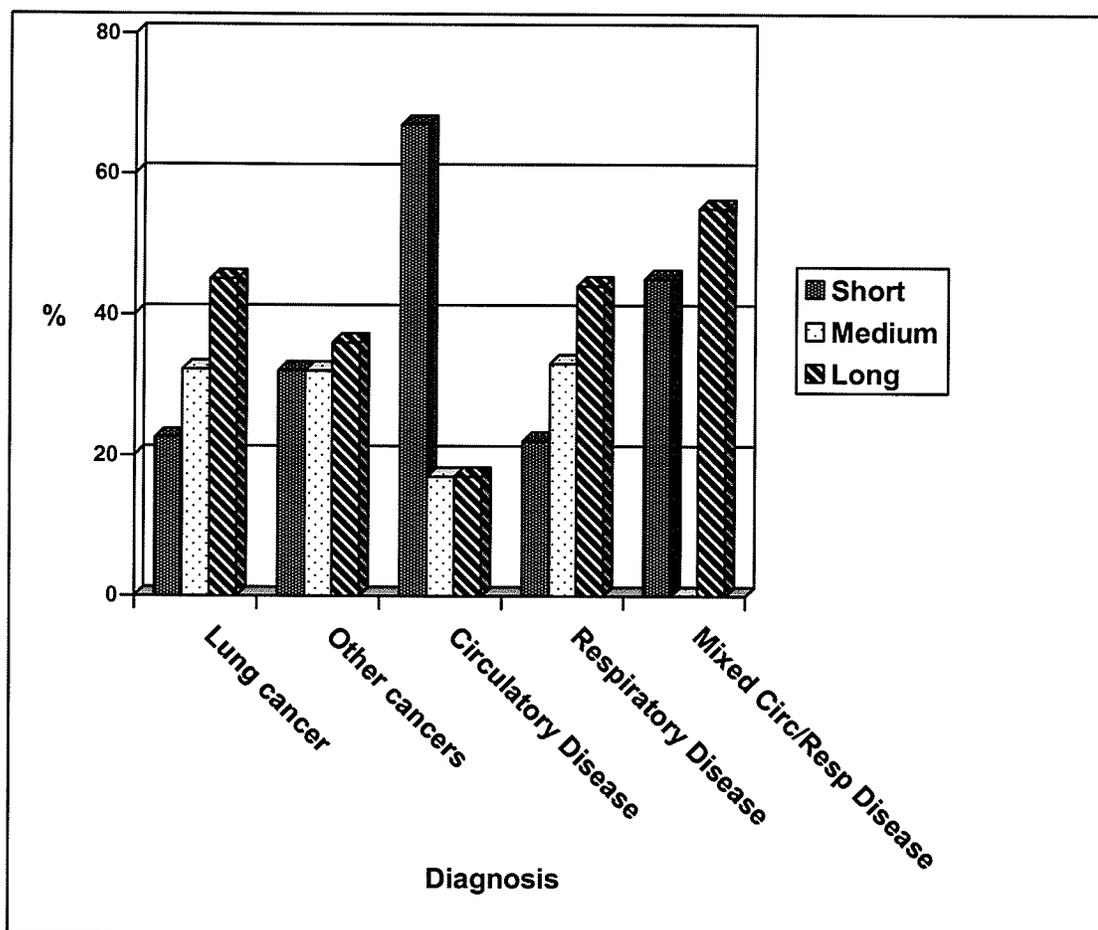


Figure 7. Duration of Care by Specific Diagnostic Category; Kivalliq Region, 1992-2003.

Note: Duration of care was characterized as short (0-2 months), medium (3-6 months) or long (>6 months). The percentage of each duration is reflected in this graph on the basis of the specific diagnostic category. It should be noted that there is a range of duration of care regardless of the diagnostic category.

Note: This data is derived from the Survey of Patients Having Received Palliative Care and is based upon 100 patients from six of the eight communities of the study area, and spans the time period of 1992-2003.

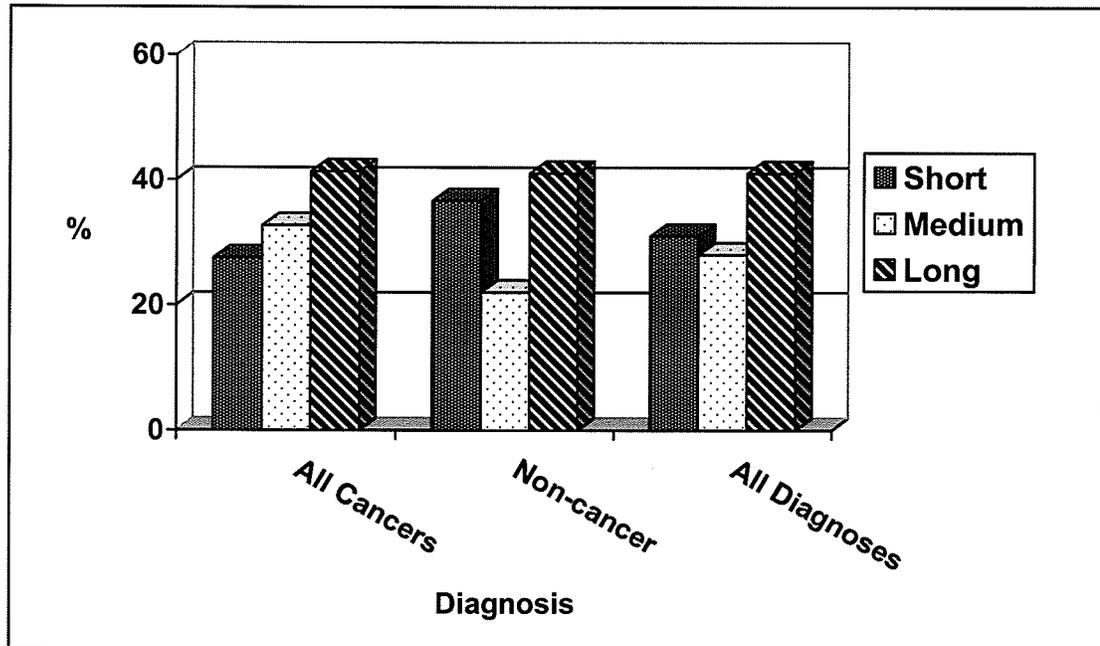


Figure 8. Duration of Care by Major Diagnostic Categories, and all Diagnoses; Kivalliq Region 1992-2003.

Note: The data presented in Figure 7 is portrayed in this figure by the general categories of all cancers, non-cancer diagnoses, and all diagnoses. It should be noted that a significant number of patients (~40%) were reported to have received palliative care for a long duration. This data is derived from the Survey of Patients Having Received Palliative Care and is based upon 100 patients from six of the eight communities of the study area, and spans the time period of 1992-2003.

The observation that significant numbers of patients received a long duration of care may be a reflection of the early institution of palliative care in anticipation of need. This is in keeping with the model of Figure 6 which identifies on careful scrutiny that the institution of palliative care may be undertaken at the time of diagnosis or presentation. This may not be surprising as the primary health care team is comprehensively responsible for care at all stages of illness, unlike other systems in which the onset of palliative care may be defined by the time of referral to a specialized programme. Similarly on the basis of the model, the early institution of palliative care does not preclude therapy to modify the symptoms or the course of the disease. This was specifically observed in the retrospective review in which two individuals were noted to die while in a tertiary care setting while undergoing advanced therapy to enhance quality of life in the face of incurable disease.

The impact of prolonged care was not identified as a determinant of the ability to maintain care at home and in the community. While fatigue of care providers including family members was discussed, the solution invariably was the recruitment and training of additional individuals. This is reflected in the following response to direct questioning of a community nurse who had provided 12 years of community service in remote communities:

Interviewer: Now, some of the people you've looked after with community members, with family members, have been ill for very long periods of time in end-of-life care. Do you ever feel a difficulty in looking after people for such prolonged periods of time?

Community Nurse: No because I have had so much support from the families.

Interviewer: From the families.

Community Nurse: And then the doctors who have helped me to control the pain, or to control whatever symptoms that present, they have been very helpful and they have been able to control those symptoms, and make the patient comfortable. And I get a lot of help from the family as far as the basic care.

Interviewer: Do you find that there is the potential for family members to burn out or fatigue from it or do you find even with the prolonged cases they do ok?

Community Nurse: We get more people involved so that they take turns, we have made a schedule on the wall, who is coming at what time to look after, so there is somebody different maybe for 2 hours or 3 hours, depending on the needs of the patient. If they require a lot of help, then we change every hour, that's as many people we get. Because we have lots of people visiting.

Interviewer: Right. And who does that coordination of scheduling?

Community Nurse: We go and sit with the family and find out who are the family members who are interested in offering help, and then we make up a schedule and ask them which time is good for you, 24 hours. And they feel good about it because they did something for that person who is no longer going to be in another 2 months.

Quantification of symptoms was not undertaken in this study. A large United Kingdom study is commented on by Seale in regards to the comparative frequency and duration of symptoms reported by individuals dying from cancer, heart disease and stroke (Seale, 2000). Despite the duration of symptoms in cancer being shorter than for other diagnoses, it was reported that cancer caused a larger number of symptoms which were considered by respondents to be more frequently distressing than the same symptoms in non-cancer terminal illness. This finding may be quite relevant to programme development in the Kivalliq Region given the burden of illness specifically related to cancer in the population group.

5.4 Age Patterns

The age of patients who received palliative care in the Kivalliq Region was evaluated by the Survey of Patients Having Received Palliative Care; data was available for 100 patients from six of the eight communities of the study area from 1992-2003. The age distribution of the patients is shown in Figure 9 and identifies that the majority of patients were in their senior years, likely being reflective of the disproportionate prevalence of chronic and terminal neoplastic illness. The age pattern is concerning as the challenges of palliation are superimposed on some general care issues for seniors. In the stated rationale for a guide for end-of-life care for seniors it is identified that underlying and complex health problems that add to the challenges of care provision (National Advisory Committee, 2000). Weakness, loss of appetite, and general discomfort are cited as concerns that may confound the symptoms specific to the diagnosis contributing to the need for palliative care, and differing narcotic metabolism a specific challenge to pain management. Accordingly, additional expertise may be required from care providers of all professions when addressing the palliative care needs in an ageing population as identified in this study. It should also be noted that a very small proportion of patients were children, presenting additional and complex challenges to healthcare providers and families in the Kivalliq Region. Specific points in the care of dying children, including those with neurodegenerative disorders and congenital abnormalities in addition to malignancy are offered in the literature (Finlay, McQuillan, & Tower, 1995). Identified are the benefits from input from adult specialist palliative care team

members in addition to close liaison with paediatric care providers. The availability of such expertise and the importance of these benefits should be assured in programme development initiatives in the Kivalliq Region.

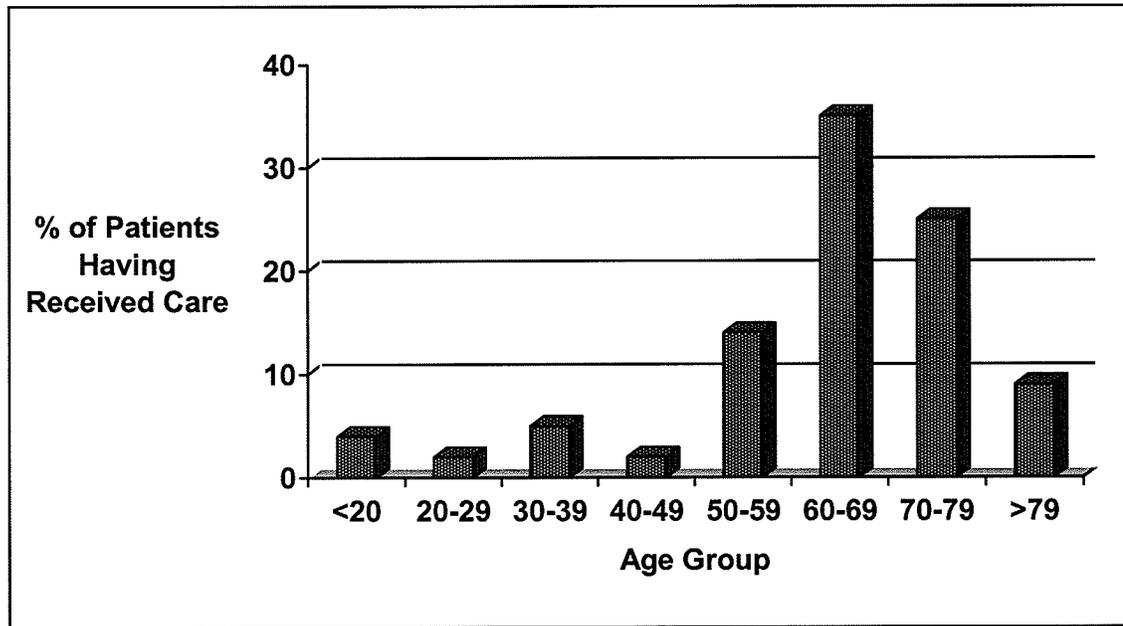


Figure 9. Age Distribution of Patients Having Received Care; Kivalliq Region, 1992-2003.

Note: The percent of all patients in each age category is identified. While the age distribution of patients reported to having received palliative care reflects services provided principally to an older population, note is made of the 4% of patients in the paediatric population with attendant challenges to care provision.

Note: The data is derived from the Survey of Patients Having Received Palliative Care and is based upon 100 patients in six of the study area communities from 1992-2003.

5.5 Location of Death

The location of death was assessed by the Survey of Patients Having Received Palliative Care. Of the 100 patients reported from six of the eight Kivalliq Region communities, it was determined that 80% of patients receiving palliative care died in their home community, as defined by: in their own home, in a local care facility, or in the health centre. The remaining 20% of deaths occurred outside of the community, approximately equally divided between the regional secondary care centre in Churchill, and tertiary care centres being Winnipeg in all but one instance. This data is presented graphically in Figure 10. This data is strikingly similar to that of Macaulay who evaluated place of death for patients with cancer diagnoses in his Kivalliq Region mortality review of 1987-1996: 81% died in their home communities, 10% in Churchill and 9% in Winnipeg or other tertiary care centres (Macaulay, 2002).

The annualized data reflecting place of death from this study is presented in Figure 11, using results from the Survey of Patients Having Received Palliative Care. No specific change in pattern of location of death has occurred through the period of review.

Survey Questionnaires of health care providers explored their opinions as to where palliative care patients died. The data is displayed in Figure 12. Of the 44 respondents, 49% were of the opinion that palliative care patients usually died in their home community, therefore underestimating the statistic of 80% identified

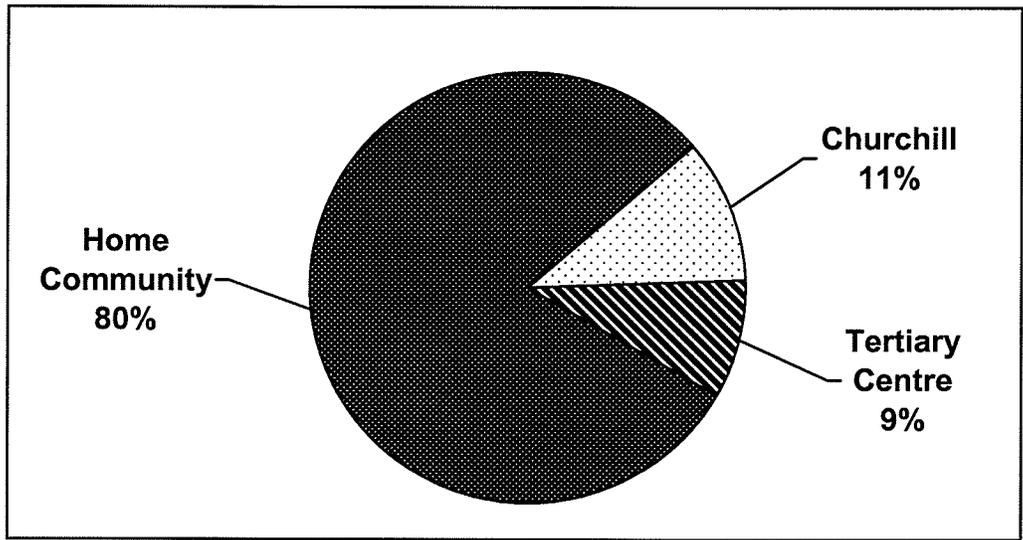


Figure 10. Location of Death for Patients Having Received Care; Kivalliq Region, 1992-2003.

Note: The majority of patients having received palliative care in the study area die in their home community; a minority died in either the regional secondary care centre in Churchill or a tertiary care centre.

Note: The data is based upon the Survey of Patients Having Received Palliative Care submitted by six of the eight communities of the study area including 100 patients and spans the time period of 1992-2003.

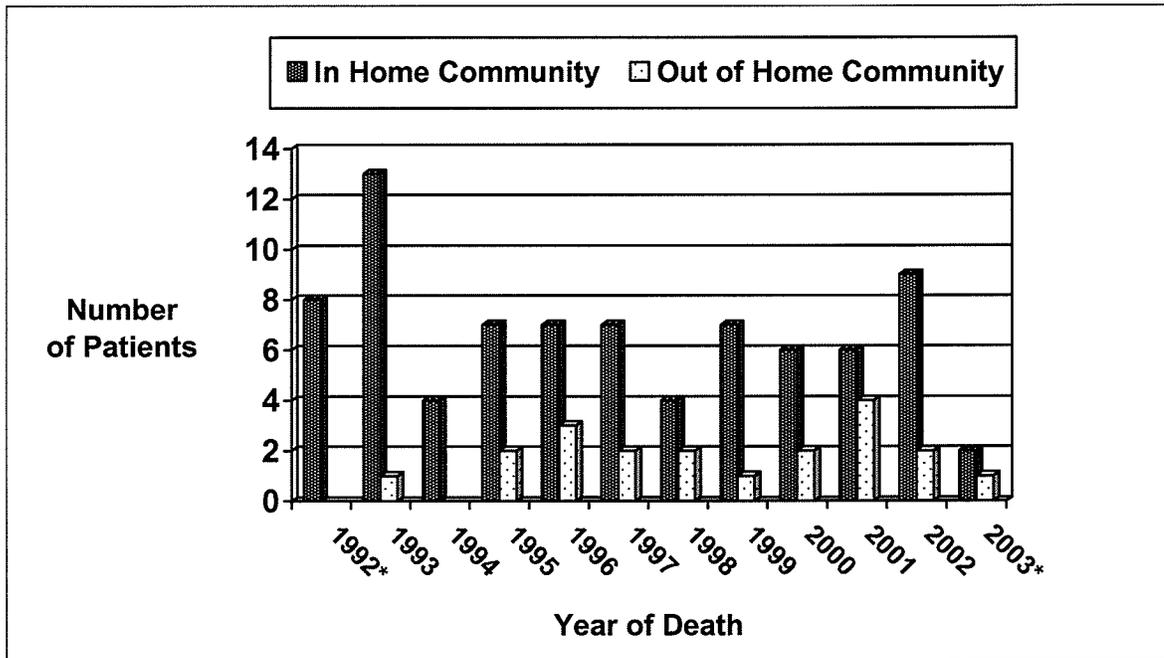


Figure 11. Location of Death by Year for Patients Having Received Care; Kivalliq Region, 1991-2003.

Note: This graph identifies the number of patients who were reported to have received palliative care and their place of death on an annual basis during the period 1991-2003.

Note: The data is based upon the Survey of Patients Having Received Palliative Care submitted by six of the eight communities of the study area including 100 patients and spans the time period of 1992-2003. (*) denotes potentially incomplete data for 1992, and partial year data for 2003.

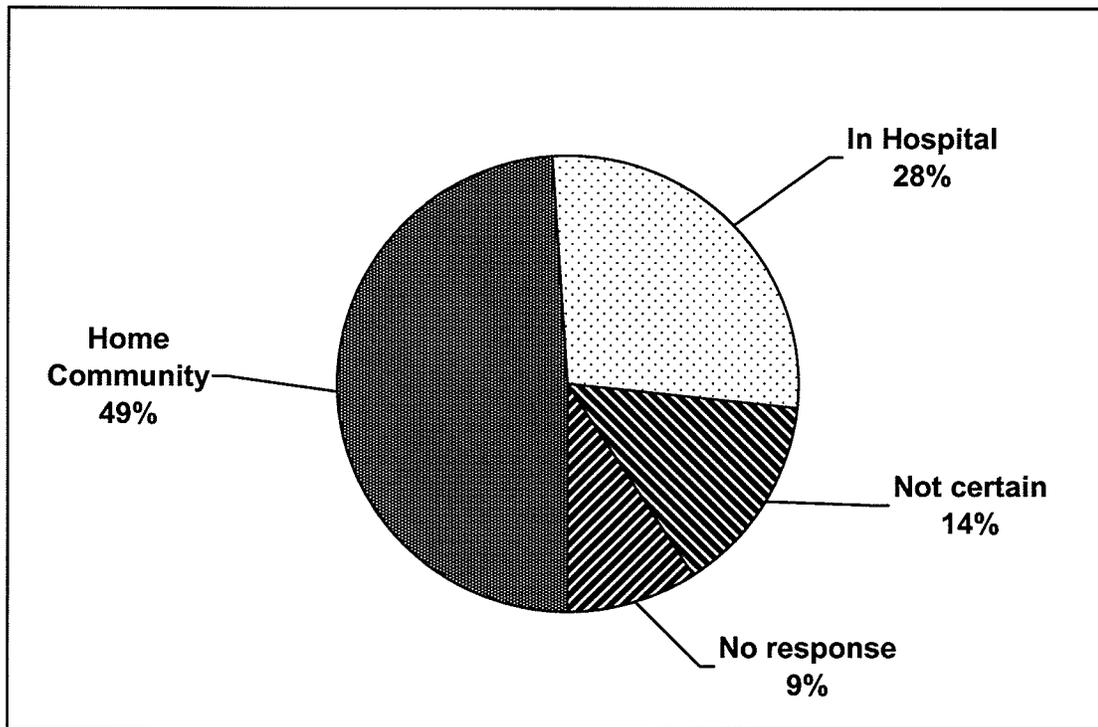


Figure 12. Perceptions of Health Care Providers Regarding Place of Death of Patients Having Received Palliative Care.

Note: Survey Questionnaire participants were asked to identify the 'usual place of death' for palliative care patients. Of the 44 respondents 49% identified a patient's home community as the usual place of death, being an underestimate of the 80% that was identified in the survey of patients having received palliative care in the study area as identified in Figure 10.

above; 28% felt patients died in hospital versus the figure of 30% as above; 14% were not certain and 9% did not respond to the question. It is hard to interpret this result given the number that were unsure or had no response. Questionnaire participants were also asked to respond to the question: "Would it be a fair statement to say that death from chronic illness has become progressively more removed from the community over the past few decades?" Of the respondents, 26% agreed with the statement, 50% were unsure, 18% disagreed, and 5% offered no opinion. Again it is difficult to interpret these results, but it appears there is the potential for more extensive end-of-life care within community settings to reduce the perception that death from chronic disease continues to be removed from the community. Similar issues regarding perceptions amongst health providers in northern First Nations settings were explored in Manitoba (Hotson et al., 1999). In that study 17% of northern physicians and 40% of northern nurses felt that patients tended to die at home. In the same study 83% of physicians and 60% of northern nurses agreed with the statement that death from chronic disease was being progressively removed from northern communities. This data may suggest that comparatively more patients die in their home community in the Kivalliq Region, and the experience of end-of-life care may be less removed from community settings and the attendant family and cultural supports than in the First Nations study settings examined by Hotson.

Opinions regarding place of death in the context of patterns of illness were offered in the open-ended questions of the Survey Questionnaire. The following

opinion was offered by a cleric who had 40 years in the profession and 19 years of experience in the Kivalliq Region:

Many - too many - die in hospital although some are able to die at home.

and:

Too often medicine has been moved to larger centers offering more specialized equipment services; palliative care patients do not need such heroic intervention; care for loved ones ought to be returned to the families and communities.

Regarding the perception of death being removed from the community, the following is offered in what may be interpreted optimistically as progressive change. This opinion was offered by a Home Care Aide during an in-depth interview:

Interviewer: They would be sent away to a hospital to die, is that true?

Respondent: Ya, it is. But today like, if a doctor tells me I have a cancer and I don't have some months to live I would just tell the doctor I will go home, but like the doctor would let me, give me a choice now. Like, the doctor would ask me, if you want to go home you can go home, if you want to stay in the hospital you can stay at the hospital. Today, nowadays.

Interviewer: And that is something you view as a good thing.

Respondent: Ya, it is, some of them say, back in late 70's, they should have watched their mom or their dad or their brothers or their sisters or their dad or their uncle, they should have seen that patient dying. Some people still don't believe that person died out of community.

Chapter 6. Capacity

6.1 Overview

The term capacity is used in this document to denote the infrastructure that may be necessary to establish and sustain a formal palliative care programme to enhance the end-of-life care that currently exists throughout the Kivalliq Region. Capacity will be discussed in broad categories that include health human resources, education, materiel resources and technology, and facility resources. The perspective of care providers and surviving relatives who were directly involved in care provision will be provided.

6.2 Health Human Resources

Health human resources were assessed as a component of the Survey of Community Resources, through open-ended questions in the Survey Questionnaires, and during in-depth interviews of key-informants. The complement of nurses, home and community care workers and others are recognized as contributing to the team approach of palliative care. A number of human resource issues will be identified.

There is the very strong perception that there are significant limitations to human resources to meet the needs of community-based palliative care. An open-ended question in the Survey Questionnaire asked respondents to identify "potential barriers to increasing the amount of palliative care that could be provided in the community". Of the 29 respondents who provided comments, a

shortage of nursing resources was a dominant theme with 14 individuals addressing the issue. Similarly when asked to identify changes "...that might allow for more palliative care services..." of the 27 respondents, 15 cited the number of health professionals as needing attention.

The number of nurses is not the sole concern identified by the Survey Questionnaire. Evaluation of the responses revealed issues of turnover of nursing staff. Of the 20 respondent nurses, the average number of years in nursing was approximately 14.5 years of which an average of 4.0 years has been spent in remote community settings. However the average length of time in their present position was only 2.8 years with a median value of only one year. Surprisingly staff turnover was not addressed as a barrier to palliative care programming, and continuity of care was addressed on only one occasion.

Concerns regarding the complement of nurses are identified in the Inuit Tapiriit Kanatami discussion on palliative care (Inuit Tapiriit Kanatami, 2002). The shortage of nurses was termed "critical" and high turnover rates were noted. The training of Inuit nurses was identified as a strategy to address nursing shortages in the long term.

The pivotal role of home care in palliative care is addressed in the literature (Bowling, 1983). It has been demonstrated that sufficient quality and quantity of home services be provided for comprehensive palliative care. Accordingly, the implementation of the Home and Community Care Programme of the Nunavut Department of Health and Social Services in 2002 brings optimism to the potential development of community-based palliative care in the

Inuit Hamlets of the Kivalliq Region. While it is recognized that unfilled staff positions were recorded in the Survey of Community Resources at the time of this study, there was early evidence that the additional resources of the programme would have a positive impact on palliative care activities. The following opinion was offered in the Survey Questionnaire completed by a relief nurse with extensive professional experience and four years practice in remote settings:

The ability to provide better palliative care services has just increased over the past 6 months with the addition of a Home Care Nurse and Home Care Worker.

The formal inclusion of palliative care in the Home and Community Care Programme work-plan and sustained funding would be deemed essential for successfully allowing patients to maximize end-of-life care at home. The programme gives ample opportunity for engaging increased numbers of Inuit in the provision of community services. Inuit staff could be initially recruited as home care workers and healthcare aides. Over time, it should be anticipated that Inuit would be educated to enter the regulated health professions including nursing that will be essential to comprehensive home care. This human resource and community development potential is in keeping with the Bathurst Mandate of the Nunavut Government that includes recruiting, training, and retaining Health and Social Services staff at full capacity in all communities and facilities (Government of Nunavut, 2000).

The contribution and importance of interpreters and Community Health Representatives (CHRs) as pivotal transitional positions bridging to the period

when more Inuit fill professional staff positions has been discussed in Chapter 2. The contribution did not go unmentioned when healthcare providers were asked to identify potential changes to allow for more palliative care. The following opinions were expressed in the Survey Questionnaire, the first by a Home Care Aide, the second by an experienced relief nurse:

language - more interpreters needed

culturally supportive interpreters

This opinion was provided by a community nurse with exposure to a number of Kivalliq Region settings regarding the essential role of the Community Health Representative (CHR):

By adding another clerk-interpreter to the Health Centre staff could allow the CHR, who is having to do a lot of clerk-interpreter work, to become more involved in palliative care services. She provides that vital cultural link with the community.

Other resources to the broad definition of health care providers included informal providers including elders who were known to become actively involved, and members of the clergy. The majority of the completed Surveys of Community Resources identified a number of individuals in each community who ordinarily become involved. The role of dedicated elders was not addressed by key-informants, however active participation by clergy through visitation of patients and family members was frequently mentioned.

6.3 Education

6.3.1 Education Attainment

Survey Questionnaire respondents were asked to identify their education relative to palliative care. Education was to be reported in two aspects: education as a student in the respondent's current profession, and education subsequent to graduation as a component of continuing professional development. Of the 44 respondents 40% indicated they received palliative care education as a component of their initial education, 12% received no initial palliative care education but received focused training as a component of continuing professional development, 15% reported both initial and subsequent education, and 33% stated they had received no palliative care education. This is presented graphically in Figure 13. Of the 20 nurse respondents, 70% had received some palliative care education; all three of the community physicians had received palliative care education in their initial training, one of whom acquired additional training as a component of continuing professional development.

Inuit members of the healthcare team had variable education in palliative care. Only 8 of 16 Inuit respondents reported receiving any formal palliative care education, three of whom received the training after commencing employment in the healthcare field. Of particular note is the fact that only 2 of the 6 clerk interpreters reported receiving any education in palliative care.

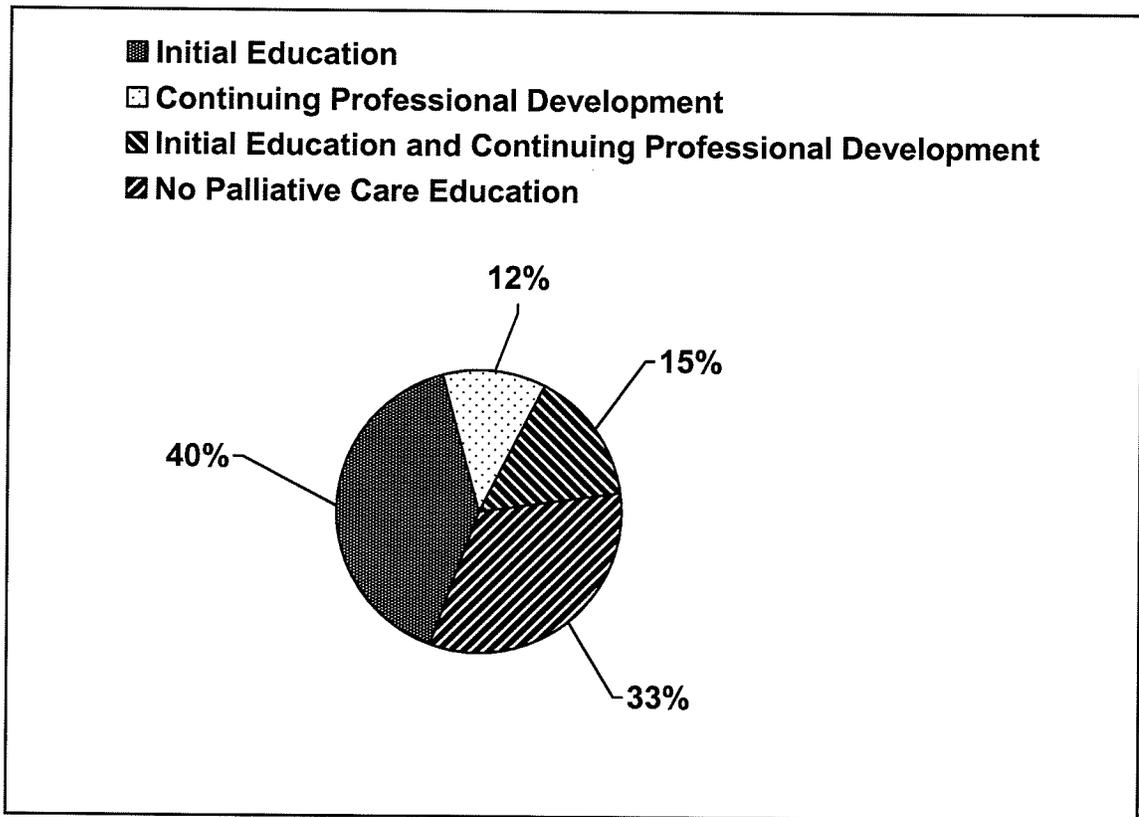


Figure 13. Education Attainment Relative to Palliative Care Among Health Care Providers, Kivalliq Region.

Note: Survey Questionnaire respondents identified their exposure to palliative care as a component of initial and subsequent education in their current health care profession. There were 44 respondents. Attention is drawn to the fact that 33% of health care providers had received no education in palliative care.

The extent and quality of palliative care education was variable for Inuit staff who received it. A CHR reported the following when asked about educational preparation for his role in the community:

Interviewer: Now [first name] you have mentioned that you are a CHR, did you do formal training for that position?

CHR: I had CHR training in 1994-95....

Interviewer: And, that CHR training included some work in palliative care?

CHR: Yes it did. And a lot of other things. But I think that was the most important thing for me to learn.

Interviewer: And did that palliative care training prepare you well for what you have done in the community since you started as a CHR?

CHR: I think it did and I think it helped me a lot, like, because I knew a little bit what to do to look after a person. And that was the most helpful thing during my workshops for the CHR.....

Interviewer: Have you learned more skills as a CHR since then in any way for palliative care?

CHR: Since I have started working at the health centre here it has helped me a lot to take care of people and, yes it did.

This positive experience is perhaps unfortunately countered by the following, which was offered by a Home Care Provider and reflective of the challenges that must be addressed by educators when preparing individuals for a broad range of clinical responsibilities:

Interviewer: Do you feel you need to learn more about palliative care? Or do you feel you are learning each day when you work ?

Home Care Provider: I learn each day.

Interviewer: Do you need to go to school about palliative care, or to a course, or are you very happy now?

Home Care Provider: Um, I don't know, sometimes I would think of maybe like a, like I already took the course before when everything [residential care facility] was open, or like ...

Interviewer: What course was that? A palliative care course?

Home Care Provider: No, how to take care of a client at their home, at their house, home care course. But I never took palliative care before.

Interviewer: Ok. When you took the home care course, was there anything about palliative care?

Home Care Provider: No.

Interviewer: Did they use the word palliative care?

Home Care Provider: Ya, they did, but I didn't understand what it means before last year when I was going to take palliative patient home care, I know what it means now but I didn't ask questions to that to my instructor. But it was a short subject, they moved onto something else.

6.3.2 Education Advancement

There was an almost universal expression of interest in continuing education in palliative care; all but one of 44 Survey Questionnaire respondents stated they would participate in palliative care education in the future. The majority of respondents, regardless of ancestry, stated that they would prefer to access the education in the community in which they were residing. Some nurses suggested taking courses in a regional tertiary referral centre, and one specifically identified preference to receiving education "in a palliative care setting". Three respondents spontaneously identified distance education as a vehicle for education, two of whom specified telehealth.

Concerns regarding skills in palliative care were identified in responses to Survey Questionnaire open-ended questions regarding barriers and potential change necessary to support palliative care. A significant theme was the need to enhance the skill set of all health providers. In the same manner, education needs of family members and the community were identified. The following are comments of a community nurse with five years of experience in remote settings, and a clerk interpreter and home care support worker respectively:

...educational opportunities for family members...

...more education re palliative care for younger people and the community...

Broader in context was the suggestion that opportunities be developed to train community volunteers in anticipation of patient care needs within the community. This concept was spontaneously proposed by a Community Health Representative (CHR) in the following context:

Interviewer: Are there any other things that you think that I should know or other people should know about palliative care?

CHR: ...like I think it would help a lot if they have more training available for [community] people to have palliative care I think that would help a lot. For the community. I think just for preparation, because if somebody needs help, there will be help available right away and they would know what to do, and that would make it a lot easier for the immediate family, and they would be able to rest more.

The relevance of this suggestion is supported by the pattern of volunteerism within the community identified in the following discussion between a surviving relative of a patient having received palliative care and the community nurse:

Interviewer: When you talk about people helping with families, you're talking about family members and they are volunteers right?

Relative: That's right, everybody is a volunteer when there is sick patient, we just volunteer and we like helping.

Interviewer: And, do you get the impression, [first name], that if there was a course that people would volunteer to go to the course?

Relative: Yes.

Interviewer: Even if it wasn't related to a family member....

Relative: Yes.

Community nurse: Because they would be better prepared to help me. When I have a crisis down here, I would go on the radio, anybody can you help me. Say for instance my support staff are all out on the land, I'll phone a few houses or I'll tell the relatives of the patient, can you get me help right now, and a whole bunch of people would come in here to help me.

Relative: That's right.

The concept of community and family member support, and their need for training, is also reflected in the following comment that was offered by the surviving daughter and care provider of a patient with cancer:

Interviewer: Ok, so you were prepared for when she came home.

Relative: Ya.

Interviewer: Tell me [first name] about the preparation. You knew that she was quite ill, but the preparation for looking after her, did the nurses help you with that?

Relative: Ya. She had to be looked after 24 hours, day and night, and we were going to take turns, we were supposed to take turns, these people in the morning and afternoon and then the other people like night shift and that. And we all had to learn all her medicine, what to take, what times, and some of the people there were also learning to do blood pressures and heart rate.

6.4 Self-assessed Competency of Health Care Providers

Survey Questionnaire participants were asked to self-assess their competency in the following five dimensions of palliative care: general competency in providing palliative care in their community, competency in managing or supporting patients with pain; competency in managing or supporting patients with other symptoms including shortness of breath, nausea or weakness; competency in managing or supporting patients with depression or anxiety; and competency in addressing palliative care from a cultural perspective. Participants were asked to assign a value on a seven point Likert-like rating scale with the gradient from “not very competent” to “very competent”; the scale is provided as a component of Table 5.

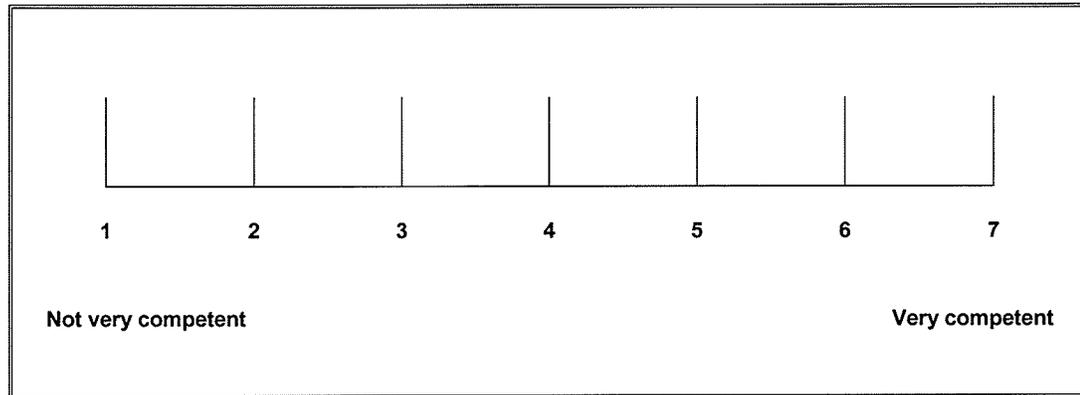
There were 44 respondents to the questionnaire; 43 of whom self-assessed their competencies in the provision of palliative care. Table 5

summarizes the results for all respondents with mean value, standard deviation, and range. It should be noted that the mean value for all parameters falls just above the middle of the seven point scale. Despite the apparent gradient in mean values between competency parameters, none of the differences reach statistical significance when compared with the general competency in providing palliative care in their community ($p = 0.12 - 0.73$).

The data was specifically evaluated for the 20 registered nurses who responded to the Survey Questionnaire; this is presented in Table 6. Although higher mean scores are noted in each parameter when compared to the self-assessed competency of all respondents, none of the differences reach statistical significance ($p = 0.06 - 0.82$). A further analysis for nurse respondents was done correlating the parameter of competency in providing community-based palliative care with self-declared extent of nursing education. The 13 nurses who identified receiving some formal palliative care education were compared with the 7 who reported receiving no palliative care training. The mean score for those with no training actually surpassed that of those with formal education; however it should be noted that the difference is not statistically significant ($p = 0.83$); the data is presented in Table 7.

The Survey Questionnaire facilitated expression of opinion regarding palliative care in the Kivalliq Region. Seven opinions were offered by the 44 questionnaire respondents regarding symptom management and cultural context of care. The following opinion of a community nurse with many years of

Table 5. Survey Questionnaire Respondents' Self-assessed Competency in the Provision of Palliative Care.



Parameter of Palliative Care	Self-Assessed Competency Value			
	Mean	SD	Min.	Max.
General provision of care in community	4.9	1.33	3	7
Pain management	4.79	1.57	2	7
Other symptoms: dyspnea, nausea, weakness	4.67	1.67	1	7
Depression, anxiety	4.42	1.56	1	7
Cultural perspective	4.41	1.53	1	7

Note: Survey Questionnaire participants were asked to self-assess their competency in five parameters specific to palliative care on the Likert-like scale identified above. This table provides the mean score in each category, the standard deviation, and the minimum and maximum score recorded by respondents. This data is based upon the 43 individuals who self-assessed their competency of the 44 Survey Questionnaire respondents. Despite the apparent differences in mean score between parameters, none reached statistical significance.

Table 6. Self-assessed Competency in the Provision of Palliative Care of Nurse Respondents to Survey Questionnaire.

Parameter of Palliative Care	Self-Assessed Competency Value			
	Mean	SD	Min.	Max.
General provision of care in community	5.35	1.19	3	7
Pain management	5.50	0.87	4	7
Other symptoms: dyspnea, nausea, weakness	5.45	1.17	3	7
Depression, anxiety	4.95	1.12	3	7
Cultural perspective	4.50	1.32	2	7

Note: This table reflects the self-assessed competency of the 20 nurse respondents to the Survey Questionnaire, and is therefore a subset of data from the 43 respondents. Despite the apparent differences between the mean values of self-assessed competency for nurses and for all respondents (Table 5), no values reached statistical significance.

Table 7. Self-assessed Competency in the Provision of Palliative Care Based Upon Educational Attainment of Nurse Respondents.

Extent of Palliative Care Education	Self-Assessed Competency Value			
	Mean	SD	Min.	Max.
Some education declared (N=13)	5.31	0.91	4	7
No education declared (N=7)	5.43	1.59	3	7

Note: The self-assessed competency of nurses in providing palliative care in their community was evaluated in comparison to educational experience for the 20 nurses responding to the Survey Questionnaire. 13 nurses identified having palliative care education in their initial training and/or subsequent to graduation; 7 nurses reported receiving no formal education in palliative care. The difference between the two groups does not reach statistical significance.

experience is representative of the 5 comments regarding the management of pain:

There is so much more out there for pain and symptom management now but there is a huge learning curve.

Opinions were also offered regarding addressing palliative care from a cultural perspective. The following statements were provided by community nurses with extensive clinical experience, yet early in their careers in remote settings:

I feel that more cultural aspects and beliefs need to be made known to care givers. This understanding will help as a nurse to understand family response to death and dying. It will also ensure that you as a nurse are providing what the patient would want and be comfortable with. It will help us to respect culture and beliefs and allow patients to die with dignity.

I think [palliative care] is a great idea and one that the Inuit are entitled to. I just think great care needs to be taken to ensure it is totally culturally sensitive and that the staff are trained well to work within those cultural values whether they clash with ours or not.

It is difficult to interpret the foregoing data on self-assessed competency in terms of true capacity to provide palliative care. There were no comparisons made to other clinical competencies, and no objective evaluation of clinical ability or standards of care. The review of the literature did not identify competency evaluations in remote clinical environments; the sole Canadian reference was the self-assessed capacity to manage an acute palliative crisis, wherein all five nurses-in-charge surveyed in remote First Nations settings stated they “felt comfortable” (Hotson et al., 1999). It is clear that whether or not the data in this current Kivalliq Region study is a valid reflection of competency, enhancement of

self-assessed competency in palliative care skill sets would seem highly desirable. Most likely this could be achieved through continuing professional development, which should undergo specific evaluation if implemented.

It is of great significance in the current study that key-informants who were family members and directly involved in the care of family members did not identify concerns regarding the clinical care provided by health workers. Additionally, health care providers who were community members identified the nurses as a support and a resource, and there were no stated concerns regarding the competency of their colleagues or the nature of the interrelationships. There were no expressed issues regarding failure to integrate cultural beliefs and patient wishes in care plans.

It would be interesting to explore if the failure to articulate concerns is a reflection of high standards of care. Other explanations could include suppression of opinion that would be interpreted as disloyal to community-based health care providers, or following the death of a family member an unnecessary and irrelevant complaint. However, it is encouraging that there were no concerns expressed regarding distressing symptoms of patients, or failure to meet the needs of family care providers; both concerns have been stated in the literature to be circumstances that often require clinical intervention and may prompt admission (Hinton, 1994a).

The World Health Organization (WHO) has stated that education is a priority for the effective implementation of a palliative care programme (World Health Organization Expert Committee, 1990). Reassuringly, the WHO provides

evidence that palliative care education can be transferred to, and incorporated into, existing health care systems. A curriculum with compulsory palliative care education is recommended by the WHO for all health care professionals, but until such a recommendation is achieved for providers in settings such as the Kivalliq Region there must be emphasis on educational opportunities that are relevant to the community-based practice environment.

6.5 Consultation Support

The need for expertise in clinical support to the management of palliative care patients was identified by respondents in the survey questionnaire. There was a need to have support from palliative care professionals, principally physicians, to support symptom management. The following is offered by two individuals, one a primary care community nurse, the other with the Home and Community Care Programme:

...need for consistent support re: pain management....

...partnerships with NMU [Northern Medical Unit] for contracting palliative care specialists. ...helpful to have consistency with prescribing MDs and consultants.

It should be noted that the support is also required when patients have been diagnosed in tertiary care environments and discharged to the care of the community. A community nurse with extensive clinical experience in cross-cultural settings responds to a question regarding discharge planning of a patient who is likely to require palliative care:

Community nurse: I haven't heard of anybody having contacted the palliative care group out of town before they got here. All I get in the reports is this patient has got CA metastasized to the liver, or the actual status of the patient, and on his discharge medications are maybe morphine p.o. tablets. By the time he comes here, a week or two later he needs more than 10mg of morphine, and whom do I contact, I contact the oncology doctor, [surgical consultant's name] or I used to.

Interviewer: So it might be useful in fact if there were formal contacts beforehand so that there would be someone familiar with the patient.

N: Yes, because he would know what the prognosis is, the palliative care team, and that would help us. The discharge plan would be over a prolonged period of time, rather than just the immediate 10mg of morphine.

The development of care guidelines was also recommended by Survey Questionnaire respondents:

Palliative care guideline/provisions are desperately needed in our Territory...

I think we need to ensure that if we are setting up a true palliative care program that we have the most current, evidence based policies and drug protocols that are out there.

The importance of these statements must not be minimized when considering development of a Regional palliative care programme.

6.4 Facility Resources

Facility resources were evaluated in the Survey of Community Resources.

In five of the eight communities there are no in-patient resources, although all communities identify that there are facilities for very short term management of any community member in need of intense care. Three communities have residential care; one is designated as an elder's centre, one a group living

environment that includes one dedicated palliative care room, and one a long-term care facility for disabled children.

In one of the two communities with a residential care environment for adults, 36 residents of the community were reported in the Survey of Patients Having Received Palliative Care as having received palliative care in the period of review being 1992-2003. Of these 27 (75%) died at home, 7 (20%) died in the elder's centre and only 2 (5%) died away from their home community. This would indicate many fewer patients died away from their home community than would have been anticipated from the data of the Kivalliq Region as a whole where the figure was 20%. The literature reports that the majority of care could be provided at home for patients with terminal cancer (Hinton, 1994b). That study also determined that there was an increasing preference for in-patient care for symptom assessment and control, and respite for family who reached thresholds of endurance for care provision and developed misgivings over death happening at home. The complementary and available resources of hospice care for such circumstances were felt to permit more confident perseverance at home (Hinton, 1994a). Further study is warranted within the Kivalliq Region where hospice facilities are available; in this study as the reason for admission to the elder's centre, duration of stay, and proximity to time of death were not evaluated. It is notable that the Nunavut Department of Health and Social Services have stated in their 2003-2004 Business Plan an objective of establishing respite facilities in each Nunavut community (Department of Health and Social Services, 2003). Realization of this objective may enhance the

opportunities for increased and enhanced delivery of palliative care within the Territory and reduce dislocation of patients from supports of family and community.

The option of in-patient care was explored in an in-depth interview of a key-informant who was the son of a woman with respiratory disease. It should be noted in this narrative that the community hospice environment did not appear to be a proffered option:

Interviewer: Did she want to stay at home?

Son: Ya. She wanted to stay home.

Interviewer: And, how did you feel about that?

Son: Well, ok a bit.

Interviewer: Ok a bit? A little bit not ok?

Son: Ya.

Interviewer: Why was a bit not ok?

Son: She didn't want to go down south to die. She wanted to die at home. That was her decision.

Interviewer: Were there some times when you would have wanted her to be somewhere else?

Son: Ya.

Interviewer: Where would you have wanted her to be?

Son: Sometimes the health centre asked her if she wants to go down South for a checkup, but she didn't want to move, go down.

Interviewer: Ok. Did she ever stay at the [community residential facility] when she was sick?

Son: No.

Interviewer: No. Did she want to?

Son: Sometimes ya.

Interviewer: Did you want her to sometimes?

Son: Ya, sometimes.

Interviewer: But she wanted to be at home?

Son: Ya.

6.5 Materiel Resources and Technology

Materiel resources in community settings were assessed as a component of the Survey of Community Resources. Six of the eight communities responded

to the survey. Additional information was contributed in response to the open-ended questions of the survey questionnaire of healthcare providers, and some information was forthcoming in the in-depth interviews of providers and surviving relatives who were directly involved in care. Review of resources identifies that most communities have basic patient care aids including hospital beds, commode chairs, and often, but not invariably, lifting devices. All communities had access to oxygen concentrators, whereas only one had a palliative care medication kit. One community reported having a portable subcutaneous medication administration pump, a device that has been identified as dramatically simplifying and improving management in a variety of clinical situations (Mount et al., 1999).

While the field of palliative care is recognized to be as challenging, demanding and complex as other fields of medicine (Seely, Scott, & Mount, 1997), the advancement of palliative care is not identified as technology dependent. There may be a natural tendency to respond to clinical care in the historical biotechnical manner, but caution against this approach is provided in the concluding statement in an editorial regarding palliative care and technology.

Mount and Seely state:

The issue is not whether, but how, to apply modern technology in palliative care. The central goal of all medical practice includes improving quality of life and relieving suffering. Our therapeutic armamentarium must reach beyond technology to achieve this end. (Mount et al., 1999)

Accordingly should there be requests for technology as a component of palliative care programme infrastructure, the request should be scrutinized in light of defined benefit and needs.

The opinions of surviving relatives as key-informants did not make reference to medical technology. They did however address the value of mobility aids to enhance independence and quality of life. The first quotation is from a daughter who was directly involved in care provision, followed by the comments of the son of another patient:

Interviewer: Are there any things that would have made it easier looking after her?

Daughter: I don't know. Maybe she had everything she needed, like she had a bed, a nursing station bed.

Interviewer: And did that make it easier?

Daughter: Ya, plus a wheelchair. That really helped her because when she wanted to look outside she would ask to be put down to the wheelchair and we would take her to the window.

Interviewer: Were there other things that would have made it easier for you [first name], when your Mom was sick? Anything else that would have helped a lot?

Son: She wanted a new walker.

Interviewer: Ok, so that would have helped?

Son: Ya.

Interviewer: Anything else that would have helped?

Son: No.

Chapter 7. Cultural Beliefs

7.1 Overview

The incorporation of cultural beliefs of patients and communities is a core value of palliative care. The WHO holistic concept of palliative care cannot be achieved without an understanding of the beliefs within a culture concerning death and dying. Integral therefore to a programme of palliative care for the Nunavummiut of the Kivalliq Region is creation of an understanding of their beliefs. A challenge exists in that there is no indexed literature that identifies Inuit beliefs, as presented in Chapter 2. This deficiency has been recognized and accordingly it is not surprising that there has been a demand for research into this area; such demands come from the Inuit themselves as articulated in the Inuit Tapariit Kanatami discussion document regarding end-of-life and palliative care (Inuit Tapiriit Kanatami, 2002).

The term Inuit Qaujimajatuqangit is used increasingly to embrace the knowledge, wisdom, values and beliefs of Inuit. Specifically the Department of Health and Social Services in Nunavut incorporates Inuit Qaujimajatuqangit not only in its Mission Statement, but also in the Departmental Guiding Principles and Values (Department of Health and Social Services, 2003). The direction of the Department in this regard is commendable as they declare the need to move from an older style of western governance and service delivery to one that is culturally appropriate to the majority Inuit population.

Inuit Qaujimajatuqangit has been explored in this study primarily through in-depth focused interviews with key-informants. Surviving relatives of patients

who were involved in care were the principle informants, but others included health care providers who were community members. These informants were from two communities of the Kivalliq Region and by design represented two distinct cultural groups of the Kivalliq Inuit. The perspective of non-Inuit providers as key-informants was also obtained. The transcribed interviews were reviewed and manually coded thematically. Additionally, some information has been obtained from the survey questionnaires that explored respondent awareness of culturally determined beliefs regarding death, dying and bereavement.

Challenges in delineating data regarding cultural beliefs are identified. Notwithstanding these challenges, the data from the mixed methods research approach has been interpreted and delineated into specific topics. Implications for programme development and specifically for care provision are identified.

7.2 Assumptions about the Other

It should be noted that there were specific challenges in eliciting information regarding traditional knowledge and beliefs during the course of this study. These challenges were manifest at times by little information coming from the key-informant. The reasons for this may be multifactorial and are postulated as noted below. The title for this section is taken from Fossett, and is reflective of her eloquent articulation of the challenges faced by researchers with reference to the Inuit of the Central Arctic (Fossett, 2001); her thoughts are taken into consideration in the following discussion.

The open-ended nature of the interview process may have provided insufficient information in the probing question to elicit a response. Frequently, but not invariably, the initial probing question did not evoke a detailed response. On occasion, discussion would follow between the interpreter and the key-informant with subsequent interchange with the interviewer. In retrospect this situation should have been explored with the interpreter. An alternative remedy was created by changing the nature of the probing question to include the value of the information in contributing to the provision of care within the community.

A second rationale could be the lack of a mutually intelligible system of communication. It is noted by Fossett that:

Inuktitut is an extremely complex and sophisticated language, which differs in all fundamentals of grammar and conceptual ordering from most European languages.

The interpreters were members of the community in which the research was undertaken. The interpreters were informed of the nature of the research and were provided with the community information document and consent forms in both English and Inuktitut. It was confirmed on each occasion that the key-informant and interpreter shared the same dialect and that the key-informant was accepting of the individual who was appointed as interpreter. Upon reflection, there was no discussion between the interpreter and the researcher specifically regarding the exploration of Inuit Qaujimajatuqangit, and in retrospect this should have been undertaken. In absence of such clarification it cannot be asserted that the linguistic divide between the researcher and key-informant had been suitably bridged by the interpreter.

A third factor may be grounded in ethnocentrism. There is the possibility that the emic position, or the insider's view of things (in this research, the key-informant) may be thought to be universal, and therefore the probing of his or her beliefs fails to elicit differences that are believed to exist in the etic position (in this research, the outsider's view).

Another factor that may bear on information sharing is that direct questioning of Inuit under some circumstances may be considered an invasion of privacy; whether or not that was the perception of some key-informants cannot be determined. Fossett explains that the deliberate provision of false information, the "telling a whopper" to an ethnographer, may be an admonishment of the questioner for behaviour viewed as rude and disrespectful. One key-informant who spoke hesitantly when questioned about Inuit beliefs thereafter related a lengthy and profoundly compelling event of travel with a dying relative to another world. While there may be no reason to doubt the informant, upon reflection his initial hesitancy to provide information may have been a clear indication that I had crossed an acceptable line of inquiry and was invading a private realm.

The degree to which the above noted concerns have influenced the determination of Inuit Qaujimagatuqangit cannot be measured. However, somewhat reassuringly there was commonality of information between key-informants which speaks to validity of data, if not comprehensiveness.

7.3 Inuit Qaujimajatuqangit

7.3.1 Respect

The concept of respect pervades the content of interviews with key-informants, both those of health providers and those of bereaved family members in both community settings. Respecting wishes is a determinant of the location of care. A typical passage from an interview with a Health Care Aide includes the following exchange:

Interviewer: [First name], I think I know the answer to this question but can you tell me, do people prefer to die at home?

Home Care Aide: Ya, they do. They always tell me.

Interviewer: They, the palliative care patients tell you that.

Home Care Aide: Ya.

Interviewer: And by home, in their own house.

Home Care Aide: Ya.

Interviewer: Right. Do you believe their families wished them to die at home too?

Home Care Aide: Um, like, Inuit have (inuktitut word).

Interviewer: You must tell me what that means.

Home Care Aide: It means that you respect the person who's dying, you are supposed to respect that.

Interviewer: Thank you.

Home Care Aide: Ya, they would, like the family would agree with the patient. Their family members of who is dying, they respect their wishes.

Respect is also the determinant of the provision of care in many realms including meeting personal health related needs and spiritual needs. There is no evidence that disrespect occurs, and although not specifically explored, the extent to which actions are carried out would infer that there is no cultural tolerance for disrespectful behaviour. Compliance with requests can be carried out at personal emotional expense by family members, but appears not to be

challenged. This is reflected in an excerpt from an interview with a family member who had provided care to relatives previously, and preferred not to be involved again:

Interviewer: When you look back and think back about the times you have looked after your father, and 2 grannies, do you think you would be able to look after other members of your family now if they were quite ill with cancer or shortness of breath?

Family member: No.

Interviewer: That's something you don't feel you could do?

Family member: No.

Interviewer: Do you think that if you had more training or more help that you could do that?

Family member: I don't think so I don't even visit anybody anymore after I saw my granny I don't visit sick people anymore.

Interviewer: [First name], what would happen if a very close relative said that they very much wanted you to look after them, and they were quite ill, what would you say?

Family member: If it's not my mom, I would say get someone else instead.

Interviewer: Ok. What if it was your mom?

Family member: If she wants me to do anything, I would do it.

Interviewer: Even though it's uncomfortable for you.

Family member: Yes.

Interviewer: Why would you do that?

Family member: Just listen to her.

Interviewer: Do you worry sometimes that you might have to do that for your mom?

Family member: Ya.

Extremes of respect for wishes are apparent when there is continued compliance with a patient's desires after his or her death. This is reflected in the following passage of a woman who was bereaved at a young age; the conversation was facilitated by an interpreter:

Interviewer: [First name], did you talk to your husband about things that he wanted at the time he was ill, or things that he wanted done for him after his death? Did you talk about those things?

Interpreter: Before he passed away, he asked her, he told her not to re-marry because they got too many kids, and if she, she told him that she was going to try and listen to him, not re-marry, and he also wanted his son to get a boat, so she bought him a boat, and another son he also wanted his son to get a snowmobile machine, she also got him one. And she respects what he had told her. And she's going to try and listen to what he had said to her.

Interviewer: Ok.

Interpreter: When he was in his last few days, he told his family not to suffer too much after he passes away because he was going to go have a sweet drink where there is another place, and he also wanted to have people to have dance, but she never mentioned it to anybody, that without telling anybody there was a dance anyways, and it was what he had wanted, and she was trying to keep the house clean the whole time and not too many stuff in the house. And there were things that he didn't like and she would not show anything to him that he didn't like. To respect what he had said.

Respect for each other is also manifest between consumers of care and providers of care. Gratitude is expressed to care providers by surviving family members and is interpreted by the provider as thanks for allowing a family to respect the requests of the deceased; this is particularly evident if there was continuing support to die in one's home or home community. There may be a hierarchy of response to requests; it would appear that the wish of an individual in end-of-life care is supreme in that hierarchy. The sense of gratification from the provision of end-of-life care may be a manifestation of displaying ultimate respect, and therefore there may be a culturally determined incentive to participate with palliative care patients. This postulation, if founded, could be a profound determinant of successful and sustainable capacity building within communities for end-of-life care. The opinion of a Home Care Aide may

contribute to our understanding of the incentive to provide care. She had been involved in the care of three palliative care patients in the preceding year and explains her reasons for continuing her work:

Interviewer: Do you enjoy your work in palliative care?

Home Care Aide: Yes I do. I like my job. I enjoy it, I like it.

Interviewer: What is the thing that makes it most enjoyable for you?

Home Care Aide: More enjoyable for me when they are sick and when they got sent back for treatment, that's when I'm happy, that patient's treatment is good and I know that patient goes home healthy and they come back healthy and I would be really happy for them, happy that they are well now, and they would be happy with me too, like, they would tell me they were mad at me because I told the person they are sick, so they go home like happy when I tell them I'm happy you're ok now.

Interviewer: [First name], you have used that word a few times, grateful, in your culture, in your community, even though they may not be a family member, after they die, do you think the family is still grateful to you?

Home Care Aide: Ya, the palliative patients is still grateful to me.

Interviewer: And how do they show to you that they are grateful?

Home Care Aide: They talk to me like the first client, the first patient's family, there is a couple of them that never used to talk to me, now they are talking to me and I know they are still grateful what I did for their family member.

Interviewer: That's what makes you smile.

Home Care Aide: Ya.

Personal fears may be suppressed and overcome by the desire to be respectful, and in acting in a respectful manner, strengths to continue with challenging circumstances may be developed.

There was no expression of concern regarding the provision of care by community members. Neither health providers nor surviving family members of patients expressed concern in this regard. This may be a manifestation of respect shown for care providers that is reciprocated by the consumers of care.

The concept of volunteerism was raised in key-informant interviews. The concept was not explored in depth and in retrospect that is an oversight that is worthy of further study. At question is the Inuit interpretation of a non-Inuit term. Members of the community in which 'volunteer' support was dominant may be articulating strong adherence to the cultural values of respect, which we have interpreted as volunteerism. If so, perhaps that is why another informant has referred to enhanced volunteerism as reflective of "strength of community", possibly being a reflection of adherence to cultural beliefs.

If respect is integral to the culture and is a determinant of actions and responses, health care providers must be clearly aware that 'compliance' of patients with a provider's request may be simply a manifestation of their display of respect. It is therefore essential that the patient's ideas, fear and expectations be explored in an open-ended approach to ensure their participation in care. This may be particularly true if decisions are made to have the patient transferred from their home community for care.

7.3.2 The Desire to Die at Home

The desire to die at home surfaced as another dominant theme from interviews with key-informants. The ability to have family and community members present, as chosen by the patient, appears to be the determinant of

that desire. This was reflected in many interviews, the following being a typical response to discussions regarding place of death:

Family member: Yes, [they requested to be at home for their illness]. They wanted to die at home where their family is. Yes, they did not want to die away from the community.

The degree to which this is expressed is strongly suggestive that the desire to die at home is culturally determined. The key-informant interviews expressed frequently that homes of palliative care patients become crowded with visitors. One key-informant, a Home Care Aide, infers that 'crowd control' might be a requisite skill set for providers:

Home Care Aide:...the community knows that that person is dying. And the patient's trying to take a rest, there is people coming in and visiting and I can't give that patient a rest Like I would say please don't wake him up I told couple people, she's sleeping, she needs to rest, go out and come back next week.

There is also the belief that the death of a loved one is hard to comprehend or acknowledge if the patient is not seen to die, or be seen to have died in the presence of community members or family. This is reflected in the dialogue with a Home Care Aide who was discussing the reasons for patients desiring to die at home:

Home Care Aide: ... if my husband was down south to go die, then I won't really believe that he died because I am not around him.

The desire to die at home as a cultural value may be the most cogent justification for locating a palliative care programme in the Kivalliq Region. The literature identifies the capacity of home care to ordinarily support patient and

family needs, particularly if there are options for respite (Hinton, 1994a); the manager of Home and Community Care as a key-informant, asserts that this statement is valid in the context of health services in the Kivalliq.

A particular concern may be responding to a patient's request to have family in attendance where members of the family have been separated from their home community. If the presence of family is a cultural value and therefore an expectation, responses to requests may challenge family members, healthcare providers and inevitably policy makers. Inevitably this should be explored in the context of palliative care.

7.3.3 “Healing Properties” of Traditional Food and “Fresh Water”

Closeness to the land may be one of the more recognizable descriptors of the Inuit by non-Inuit. This was a dominant theme in key-informant interviews, though lesser than the preceding concepts of respect and dying at home. While not as dominant a theme in interviews there was clear indication of the importance not only of the land, but also the products of the environment, being “fresh water” and the products of a “hunt”. Freely offered in key-informant interviews was the importance of “country food” and fresh water to those who were in end-of-life care. The term “healing property” may be a misinterpretation, as there is no suggestion from narratives that there could be a reversal of the disease process, there is a strong implication that the patient “felt better” as a result of eating country food. Compliance with requests to secure food and water may acknowledge the cultural value of respect, but it may also speak to the belief

that traditional foods and fresh water is a contributor to wellbeing, perhaps therefore a cultural belief in its own right. An Inuk elder who was a community cleric offered the following information through an interpreter during discussions regarding beliefs:

Interpreter: Ya, for some white people and Inuit, we all have the same feeling when we lose a relative, but as Inuit, when there is a sick person and dying, and if that person asks for traditional food, anything, like if let's say he asks for caribou meat or fish or geese, or anything like that, and is giving a fresh made right away, he can get better even without medication. That's what he truly also believes in because he has seen that happen. A very sick person might start dying in his last few days but when he asks for traditional food and it's given right away then the elders or the people back then would call it medicine. Even though it's not a medicine, as a traditional way of life.

An implication of the importance of country food and fresh water in palliative care programme development is ensuring that securing traditional food and fresh water for palliative care patients is a component of responsibility for the family and community. This may be unique in programme development when compared to other Canadian settings, but if the healing property of traditional food and fresh water is viewed as a cultural belief it should be incorporated into service programmes.

The implication for tertiary care centres may be significant as well. When the patient is acutely ill and out of their home environment the importance of traditional food and fresh water may be of great importance. Securing and maintaining a supply of traditional food may be a challenge, but a necessary one if cultural beliefs are to be truly supported. It would appear that this is being

acknowledged in tertiary care settings, as evidenced by the discussion between the researcher, the interpreter, and a family member who was a provider of care:

Interviewer: [First name], when your parents were sick and you had to go to Winnipeg with them ...

Surviving daughter: Yes, lots of times.

Interviewer: Did you take food with you?

Surviving daughter: Yes, I had to take food with me all the times.

Interpreter: And the staff down south where we stay, the boarding home, they know mostly the traditional stuff now. They learn quite a lot about the traditional food and fresh water. There is always fresh water there and traditional frozen food, like caribou or fish.

Interviewer: Would the traditional food have to come from this community.

Surviving daughter: Most of it comes from here.

Interviewer: Most of it comes from here, but if the patient came from here and there was traditional food from [another community] that would still be OK.

Surviving daughter: Yes, along as it is traditional food.

7.3.4 Sharing Bad News

The sharing of bad news was explored by both direct and indirect questioning in key-informant interviews. The rationale for departing from open-ended questioning was to specifically explore this topic as concerns are expressed in the literature regarding the potential for discord in this realm. It is stated that:

The analysis examines conflicts which occur between clinicians, who formally emphasize bioethical principles of autonomy, and patients and families, who apply alternative values and emphasize communal solidarity. (Kaufert et al., 1999)

The key-informants consistently advised of a 'protocol' whereby health care providers who are in a position of sharing bad news must first approach a family member; it is that individual's responsibility to seek counsel from "family" to

determine the timing of information sharing, who should be present when information is shared with the patient, and what specific information is to be shared with the patient. It should be carefully noted that the key-informants did not suggest that bad news not be shared with the patient. It should be equally clear that a diagnosis of 'cancer' has no particular bearing on the sharing of bad news, and therefore not specifically stigmatized by community or family.

The following is a discussion with an interpreter who was also a surviving relative who was directly involved in care provision. She summarizes the protocol for sharing bad news, but also continues onto discuss the importance of language interpretation:

Interviewer: Ok. Are there other things that people should know? Do you think people want to know, do patients want to know when they're passing away, do they want to be told from the doctors and nurses about their illness?

Interpreter: Maybe they prefer to let their relatives know first and see if they want the patient to know about the illness. That's normally the Inuit way.

Interviewer: Normally the Inuit way.

Interpreter: Ya.

Interviewer: Is to tell the relatives first, and then have the relatives decide. And then who would decide, [First name]?

Interpreter: Either the father or the oldest son or daughter.

Interviewer: And so, the doctors should ask the husband or wife or the oldest child, they should ask them what the patient would want.

Interpreter: ya.

Interviewer: And, should the doctors and nurses be told they should respect that decision?

Interpreter: Yes. Very much.

Interviewer: They should. Some doctors feel that they must tell their patients bad news, but you're tell me they should make sure it's checked first with the husband or wife or the oldest.

Interpreter: Ya.

Interviewer: So if there is going to be a meeting, am I correct in saying it should be with family members first?

Interpreter: Yes.

Interviewer: But, that doesn't mean, if the doctor is told that it's ok to talk to the patient, that's acceptable.

Interpreter: Ya.

Interviewer: But they should have permission first, am I correct?

Interpreter: Ya, and if they are going down south for a check up, they should always have escort who speaks English and Inuktitut. It's very hard to be a interpreter. I had to be interpreter when I was gone for medical and a girl from Sanikiluaq and I don't know how to talk that dialect.

Interviewer: So that when the doctors are using an interpreter, the interpreter has to be the right dialect.

Interpreter: Ya. Because sometimes we might misunderstand and misinterpret.

Care providers must not absolve themselves of sharing bad news. If there is a situation that has the potential for cultural conflict, the literature suggests the following three options: using strategies that allow the patient, the family members and the providers to clarify their values; engage consultants with special knowledge of the culture and ethical decision-making frameworks to be used as mediators; and lastly the use of language intermediaries who can maintain neutrality and provide technically proficient translation (Kaufert et al., 1999). It would appear that any of those options singly or in combination could be valuable in the Inuit circumstance of sharing of bad news. Clearly the situation to be avoided is represented in the exchange between the interviewer and the daughter of an individual with prolonged in-hospital care in a tertiary care centre:

Interviewer: You were in Winnipeg a fair bit with your Mom weren't you?

Family member: About 5-6 weeks.

Interviewer: Did anybody tell you your mother might die?

Family member: They didn't tell us anything until the last few days when we were going to be home. It took them how long to finally let us know.

Interviewer: Did it take them that long to find out what was wrong?
Family member: That I didn't ask. But what thought, like, she knew something was wrong, but they wouldn't tell her when she tried to ask. But they wouldn't really tell her what's really wrong because all they kept saying was that she had something to do with the liver.
Interviewer: Oh.
Family member: But they have to put a stent inside her, that's all they told us about. But they didn't tell us about her pancreas cancer until about maybe 3 weeks, 4 weeks later.
Interviewer: Oh, that long after. And they did not talk to you about how long she might live?
Family member: No, they didn't say.
Interviewer: Ok. When you were in Winnipeg, did you have a translator or interpreter working with you?
Family member: When I would bring her to the, like when I go to the hospital with her, one of the interpreters used to try and let me interpret for my Mother.
Interviewer: Oh.
Family member: She was supposed to be the one to do it. But then I asked for another interpreter, that's when . . . I didn't understand ... like I couldn't understand. So I was with another interpreter.
Interviewer: Ok. So you couldn't understand in English.
Family member: Not really much. I do but when it comes to hard words it's hard.
Interviewer: But the interpreter went with you once, or sometimes, to talk about it. But even then, the doctors didn't talk to you even with that interpreter about her dying?
Family member: No, they didn't tell me.
Interviewer: Until you came home.
Family member: Ya.

It cannot be asserted that the concept of sharing bad news should be considered a cultural belief; what can be stated is that the manner of sharing bad news could be considered cultural wisdom and thus a component of Inuit Qaujimaqatunangit. Accordingly, health care providers must be aware of an approach to offering truth that should incorporate desires of the family and the individual.

7.3.5 “After-Life”, “Going On” and the Period of Bereavement

Reference was made to the concept of an “after-life” in response to open-ended questions probing cultural beliefs. It is of note that the conceptualization of the nature of after-life is analogous to the concept of heaven of Christian belief; there may be similarities between the two belief systems, or an incorporation of Christian beliefs into pre-contact Inuit cosmology. Regardless, there is the belief that life is better “on the other side” and there is expressed optimism for patients who die following a period of prolonged or significantly burdensome symptoms. An interpreter provides information on behalf of a recently bereaved family member:

Interpreter: One of the main concerns is if they find out that there is a patient who finds that they have a cancer, and after they pass away, to let the family know that there is nothing they can do, if they die it's done and not to be sad about it forever. Because you have to think of your family and the life ahead of you, and to let them know that we have to go on, we have to live on, go on, and the only thing that she couldn't handle was when somebody told her you don't even feel sorry for losing your husband, somebody told her that and it really hurt in her heart. That was the only thing that she couldn't handle when somebody told her that she didn't feel sorry for her husband. Because she didn't want to let it show She has lost quite a number of her family, like her parents, her brothers and sisters and brother in law and her husband, and there has been some people telling her that she always seem to be happy, it's because she was told that there is life after death, and when they do good on earth they know where they will go. And that one day they will follow them. That's what she understands.

Interviewer: Is that understanding a religion understanding, or is that understanding an Inuit understanding?

Interpreter: Both. The Inuit and the Priest. A long time ago when her father was alive, he would tell her that we have a soul, and she is the youngest in her family and she has an older brother who is still alive, and it's from both the Inuit and the church.

The feelings of key-informants towards bereavement support were explored given the inclusion of engagement and support for bereaved relatives as a component of palliative care activities. Valuable insight was provided in direct response to this inquiry. In one community it was stated clearly that exploring the feelings of the bereaved was disrespectful in the immediate period following death of a family member. Visitation was deemed acceptable and welcomed at any time for support; however direct questioning specific to bereavement is avoided by family and community members. After a period of time, as "sensed" and "known" to friends, it is acceptable to inquire. The period of time could not be specifically quantified, but at minimum a number of months. There was the strong suggestion that Inuit have a need to "move on" following the death of a loved one; a period of reflection without intrusion may allow for moving on. The following is an exchange between an interpreter, a cleric and the interviewer that manifests the pattern of interaction between people following a death:

Interpreter: Remember we mention it, not to ask a relative how are you, during the first few days after the person die, but it would be ok to ask after about 3, 4 months. Something like that.

Cleric: Yes, so there is not, but they need the support, but in different way. In the south you need sharing, like I know that they make whole family together and they share about what happened to this person, and all, but Inuit culture I don't think so that way is not working. For them it's more silent way. To be with them is more important. Just be with them and they know why I'm here.

Interviewer: Do you agree with that [interpreter's first name], that just that is ok?

Interpreter: Yes, that's the way it is.

Cleric: Ya, go and ask how are you feeling, and then I don't think so, that would disturb her more than helping her.

Interpreter: Ya, that's right.

Interviewer: So you can be with each other and that's providing support, but speaking of it is not . . .

Interpreter: It would be still too fresh to talk about.

Cleric: When the time comes, she will talk about it. She will said, I miss mom a lot. That's my experience I had. I didn't talk to this person but she's the one come in and said Sister I miss my mom a lot. Then it has to be come from her, not I impose her to, how do you feel.

This revelation of Inuit Qaujimagatuqangit regarding approaches to bereavement support is of value in establishing programme guidelines. Programme directives must incorporate a general knowledge of the sensitivities regarding bereavement, but must also permit appropriate approaches to patients and their families.

7.3.6 The "Sensing" of Comfort and Discomfort with People

An emergent theme in one community setting was a concept previously not known to the researcher. It was stated by a number of key-informants and re-iterated by the interpreter that there is a phenomenon of a person in end-of-life care sensing comfort or discomfort when being with specific Inuit people. The presence of a person who is "sensed" as discomfoting can cause the patient distress and in some circumstances aggravate their well-being. There is no predetermined cause for the discomfort, and it may occur between individuals who previously had a good relationship, and may occur with an individual previously unknown to the patient. The "sense" is said to remain unchanged through the course of the illness. Key informants stated that this phenomenon is known to the Inuit, and the wishes of the patient regarding visitation by

individuals are respected on the basis of the belief. It is noted that the custom of “visiting without knocking” does not apply in the home of a terminally ill patient, and permission is requested to visit in respect of this phenomenon. The sense of discomfort is stated never to occur between Inuit and non-Inuit. The following passage provides some details of the belief as reflected to the interviewer by an Inuk elder through an interpreter:

Interpreter: From what he has experienced in the past, as he was losing his wife, during her last few days she was always in bed, always day and night, always in bed. Sometimes Inuit come to that house to help with whatever they can, but for that sick person, if a person walks in for some reason, the sick patient can feel it in her body or the body that it is very comfortable seeing that person, they might get worse or they might not say it but you can tell as soon as that person walks out, and another person walks in, then it's very different. Like you can talk to that person, you feel comfortable talking to that person, and you can tell that person to tell that first person that if it's all right with him or her not to come to the house because it makes him feel worse. He have experienced that in the past. That's one of the traditional way of life as Inuit.

Interviewer: And so would I be correct in saying that if that is a traditional Inuit belief, that should be respected?

Interpreter: Ya, he thinks it's true and he would appreciate it if you would let the doctors and nurses know down south about this so they know how the Inuit way of life is when a sick patient is on their last few days, let them know about what he was just saying. Only the sick person would feel the discomfort, but the rest of the relatives wouldn't feel anything about it. He experienced that only the sick people have this feeling. He wants you to know that it is completely different for a white person to walk in there and the Inuit patient will not have any discomfort. Because he's from out of town. But for Inuit it's a strong feeling.

This belief was independently expressed by a recently bereaved family member:

Surviving daughter: That's when my parents got sick, they let us know that they talked that when other people, when you go out, like going to the store, so anywhere we're walking out and a person sees you and comes to you and asking you, "I'm sorry it is hard for me to visit, your father or your mother might not be feeling too good if I walked in." Then we know they are not saying "I don't care about these people", they're not saying that, but it's their feeling. They think that they might make the patient feel more uncomfortable when you walk in. That's what they are worried about so they don't make the person more sick.

There are specific implications for palliative care programming. Although it is stated that Inuit are comfortable with care providers from their home community, an over-riding criterion of acceptance is the sense of comfort between provider and patient. Hence assignment of responsibilities to medical escorts, care workers or volunteers must be done in keeping with the expressed desires of the patient in light of this belief. It may be reassuring to reiterate that the sensing of discomfort does not occur between Inuit and non-Inuit, and hence would not independently interfere with the provision of care by non-Inuit health providers.

7.3.7 The Immortality of Soul

A prevalent theme in discussions between health providers centred on the Inuit tradition is the assigning of the name of a recently deceased individual to a newborn. Direct questioning of key-informants was done to identify the contemporary practice, and to corroborate the interpretation provided by Fossett; who discusses the issue framed by details regarding the ancient Inuit ideology of existence (Fossett, 2001). In this pre-Christian conversion belief, living creatures

were invested with souls, which resided for all eternity in the name. Souls were immortal, and capable of infinite reincarnation into new physical bodies. Hence death was of little importance, as the soul-name would only be temporarily withdrawn from a physical body to be brought together at a later time by the union of a new physical body and an old soul-name.

A key-informant was able to offer his knowledge regarding the practice:

Community Health Representative: And, from what I heard is that the person who died, if they wanted to be named like they can appear in people's dream, and if they dream of this person and when this person tells the other people and like, the older people, and that's how they would name the child or if they request ahead of time and they would be named through one person's child.

While beliefs in the immortality of the soul may not have immediate implications for care, the practice of naming may continue to be of interest because of the historical construct of soul and immortality.

7.4 Inuit Practices In Preparation of the Body and Handling of Personal Effects

Survey Questionnaires of health care providers were reviewed for content regarding cultural beliefs. Information that was interpreted to reflect practices was summarized. The most frequently stated opinions included preparation of the body by family or women elders of the community. Burial within a day of death was mentioned by a number of individuals. The distribution of clothing away from the surviving family members was noted, as was disposal of all personal effects by burning.

7.5 Care Providers' Knowledge of Cultural Beliefs

Knowledge regarding cultural beliefs of individual patients and their community is essential if the holism of palliative care is to be addressed by care providers. This study surveyed healthcare providers' knowledge through the Survey Questionnaire. Survey participants were asked to identify if they were aware of culturally determined beliefs, and if so to identify what those beliefs were. 53% of respondents stated their awareness of beliefs and 80% described the beliefs. The patient's desire to die at home was identified by 75% of respondents, being the dominant belief reported. Only one respondent identified another belief revealed in the interviews of key-informants, that belief being the existence of 'heaven'. In study of health providers in Manitoba First Nations, the majority of respondents believed there were traditional beliefs, but only 20% of nurses and no physicians reported what those beliefs might be (Hotson et al., 1999). There should be caution in interpreting the difference between the two cross-cultural settings. What is important is that health care providers become aware of the cultural context of their communities, and explore the beliefs of individual patients and families that would impact on care provision within that environment.

Chapter 8. Study Limitations and Study Significance

8.1 Study Limitations

The intent of using mixed methodology research for this study was not only to enrich the data from each domain but to allow convergence of information. It should be recognized that there are inherent limitations to each component of the research strategy and these are discussed from a theoretical viewpoint in Chapter 3.

Specific limitations to the study are imposed by the sample size of the in-depth interview of key-informants. A principal intent of the key-informant interviews was to enrich the quantitative domain. The number of interviews obtained and the profile of key-informants should not be considered inclusive or necessarily representative of individuals throughout the Kivalliq Region. Additionally, relatives of patients who had been identified as having received palliative care were selected from only two communities, and given the cultural diversity within the Kivalliq Region the transferability of data is limited. The potential for selection bias of key-informants by nurse managers is present; as there was no structure to the selection, and volunteers may present a bias of willingness following positive experience with the health care system in general and the provision of palliative care specifically. It is recognized that patients receiving palliative care were not participants in this study and this was a conscious decision given the methodology of the research and the limited time that was spent with informants. While it was hoped that the perspective of their surviving relatives who participated in care would serve the needs of this

research, future participation of Inuit living in end-of-life situations would enrich our understandings of palliative care for this cultural group.

The limitations of the Survey Questionnaire have been addressed not only in the chapter discussing methodology, but also in the thematic presentation of findings. The respondents broadly reflected the health professional categories that comprise the multidisciplinary team of the Kivalliq Region primary care model. However the representative nature of the sample is unknown due to absence of a formal sampling frame. The deficiencies of the Survey of Patients Having Received Palliative Care have also been addressed elsewhere but should be restated. There has been no process of validation regarding the nature of care that was received by these individuals. Accordingly, conclusions drawn from data derived from that survey tool may not be transferable to other jurisdictions, and may not be comparable to reviews of palliative care service provision elsewhere. Notwithstanding the significance of this concern, it must be appreciated that health care providers have interpreted the care as palliative in the context of their clinical and community environments. Further study should be undertaken to explore the nature of care that has been designated as “palliative” in this study.

The expressed intent of this study as reflected in the title and study objectives was to explore the determinants of palliative care programme development and implementation in the Kivalliq Region of Nunavut. The transferability of study results beyond the Region is significantly limited. The Kivalliq Region is geographically and culturally unique, and the health and social

services system has evolved to specifically address that environment. However what may be transferable is the methodology of review and the resultant approach to formulation of recommendations to guide similar health jurisdictions in the structuring of community-based palliative care.

8.2 Study Significance

The health and social services system for Nunavut is undergoing dramatic change pursuant to the creation of the Territory in 1999. The elements of change reflect responsiveness not only to demographic and cultural needs, but also to the political ideology of the Nunavut Government which is embodied in the Bathurst Mandate. This study has been conducted in that environment of change. The realm of palliative care can be thought of as ideally suited to reflect the needs and aspirations of a population group, as cultural values and beliefs may be most evident during end-of-life events. Therefore the greatest significance of this study may be the provision of foundational knowledge that could contribute to the development of a formal palliative care programme for the Nunavummiut of the Kivalliq Region. It is also of significance that this study may be the first that has explored the provision of palliative care in a Canadian Inuit population. Although data and conclusions have limited transferability, the study methodology may benefit other jurisdictions that wish to respond to palliative care needs. The study may become the catalyst for further research regarding palliative care and the cultural beliefs that are integral to holistic care.

Chapter 9. Recommendations

The intent of this study has not only been reflected in the title, but also manifest by the stated study objective which included the gathering of foundational information relevant to the provision of palliative care in the Kivalliq Region. This chapter is meant to serve not as a conclusion but as a compendium of recommendations that derive from the information acquired through the course of the study. The sources have included not only the literature and a review of the environment of the health system, but also the rich contribution in the narratives of key-informants who represent health and bereaved family members, and thus the Nunavummiut of the Kivalliq Region.

9.1 Organization for the Provision of Palliative Care

The provision of palliative care has been explored in this study in a number of dimensions. It is apparent that health care providers, and family and community members, perceive that care is not only required but is provided in response to needs. Additionally there is an excess burden of illness for both neoplastic and chronic disease that has become a stark reality to communities and their care providers. The current model of primary care while both comprehensive and interdisciplinary is being shaped not only by demographic and geographic realities but also by the changing political ideologies that speak to holism and capacity building within the Territory. These characteristics are synchronous with the holism of palliative care and the structure of palliative care

programmes. In this broad gestalt it seems timely to move forward to provide support and give structure to existing palliative care activities by encouraging the Nunavut Department of Health and Social Services to establish a formal palliative care programme. A programme could build on the services and infrastructure of the established Home and Community Care Programme. There would be a need for dedicated financial resources, defined programme objectives, and a rigorous evaluation framework; the latter such that outcomes can be made available to similar cross-cultural and geographically remote settings. There is an existing national hospice palliative care programme framework based upon norms of practice; this template should be scrutinized and thereafter adapted to meet the specific needs and realities of the Kivalliq Region. It is sensed that the vast majority of care can be provided within the Territory to prevent dislocation of patients from family and cultural supports during end-of-life care. The World Health Organization schema for palliative care could be achieved within the Kivalliq Region. The programme model includes: home care that is currently emerging programmatically; day care that could be accommodated by existing resources in three Kivalliq communities and supplemented by respite resources that are a stated objective of the Department of Health and Social Services; in-patient resources that will be available upon completion of the facility in Rankin Inlet that is currently under construction; and consultation services that should be made available within the current relationships with Manitoba as facilitated by the University of Manitoba and the Winnipeg Regional Health Authority. Human

resources could be progressively provided by the Kivalliq Nunavummi and supplemented where necessary by other individuals with specialized skills.

9.2 Education

This study has reported on deficiencies in education specific to palliative care that are acknowledged by health care providers of the Kivalliq Region. The study has also revealed a willingness of those providers to pursue additional education. An education strategy should incorporate the recommendations of the World Health Organization and focus not only on health care providers, but also families and communities. Educational needs of Inuit health care providers should be addressed by enhanced curricula that have compulsory and relevant palliative care content. There should be a response to the stated desire to build capacity within communities to develop a pool of “volunteers” with foundational skills to support the patients and their families, and assist health care providers to meet needs; this would be particularly beneficial in circumstances where the illness trajectory is long or the symptoms severe and thereby jeopardize the ability of a patient to remain in their home environment. There is a need to enhance skills of existing healthcare providers and ensure their knowledge is current and consistent with existing guidelines and protocols in palliative care. Delivery of education in Kivalliq Region communities is strongly recommended as this is compatible with the desires expressed in the Survey Questionnaires of this study. The use of new technology should be explored, including the telehealth network that has been established in Nunavut. Education should also be

provided by the Nunavummi of the Kivalliq Region and their health care providers to their health care colleagues in referral settings to enhance awareness of the unique geographic and cultural influences on the pattern of care.

9.3 Research

This study may well become a catalyst for continued palliative care research not only amongst the Nunavummiut of the Kivalliq but in a broader realm. The limitations of the study are acknowledged, both in scope and geographic focus. There is a need to specifically explore the current extent and nature of services that primary health care providers have identified in this study as “palliative care”. There must also be an identification of existing and projected needs of health care providers, patients and their families, and the broader community.

Inuit Qaujimagatuqangit has only been superficially explored, sufficient only to state that research should be continued. Most appropriately this should be done with Inuit researchers with supports as may be required and requested. Formal ethnographic approaches should be undertaken. Specific exploration of end-of-life experiences should be established in the same manner with case study strategies with patients, family and community.

The Inuit Tapiriit Kanatami (ITK) has identified the need for research in the realm of palliative care, with a stated focus on Inuit Qaujimagatuqangit, development of a model of care, and evaluation of service delivery. Partnerships with ITK should be undertaken to explore specific topics within their broad

research agenda. Liaisons should also be established with other Inuit jurisdictions not only to enrich the research findings, but also to raise the profile of palliative care for populations and communities in need.

Chapter 10. Conclusion

This research study has explored palliative care in the context of the uniqueness of the Kivalliq Region of Nunavut. The study objective was to gather and record foundational knowledge that could contribute broadly to the development and implementation of a palliative care programme specific to the needs of the Region's residents. This was achieved using a mixed methodology strategy.

The study commenced with a review of the literature which is particularly limited in the realm of cross-cultural palliative care service delivery. The organization and structure of the health care system was also reviewed, which revealed an evolving health and social services system in Nunavut that could be responsive to needs in the Territory and benefit from national initiatives that may impact positively on palliative care.

Data collection identified a substantial burden of illness from both neoplastic and chronic disease. The data is suggestive of prolonged illness trajectories with the majority of care being provided in home communities with family and community members augmenting clinical support from primary care providers. The capacity to address needs is challenged by high turnover of professional staff. There are self-acknowledged education deficits among multidisciplinary team members but there is a near universal desire for learning opportunities surrounding palliative care. Despite these challenges, clinical support purported to be palliative care was well accepted and there was no

evidence of concern about the nature of care. This finding is specifically deserving of further study.

Inuit cultural beliefs were explored with key-informants and there was a significant exchange of information that has relevance to care providers if they are to address end-of-life care in a culturally sensitive manner.

The study concluded with recommendations that are derived from the information acquired through the course of the study. The recommendations address programme development, education and research in a broad sense.

It is hoped that the study will be a significant contribution to the Kivalliq Region communities and their leadership, and provide a foundation of knowledge to be considered in the future direction in palliative care for the Nunavummiut.

References

Archibald, L. & Grey, L. (2000). Evaluation of models of health care delivery in Inuit regions. Ottawa, Canada: Inuit Tapirisat of Canada.

Bjerregaard, P. & Young, T. K. (1998). The Circumpolar Inuit: health of a population in transition. Copenhagen: Munksgaard.

Bowling, A. (1983). The hospitalisation of death: should more people die at home? Journal of Medical Ethics, 9, 158-161.

Canadian Hospice Palliative Care Association (2002). website [On-line]. Available: www.chpca.net

Carstairs, S. & Beaudoin, G. (2000). Quality end-of-life care: the right of every Canadian Ottawa.

Creswell, J. W. (1994). Research design: qualitative and quantitative approaches. Thousand Oaks, California: Sage Publications.

Creswell, J. W. (2003). Research Design: Qualitative, quantitative, and mixed methods approaches. (2nd ed.) Thousand Oaks, California: Sage Publications, Inc.

Damas, D. (1968). The People of Hudson Bay. Part II: The Eskimo. In C.S.Beals & D. A. Shenstone (Eds.), Science, History and Hudson Bay (pp. 127-200). Ottawa, Canada: Queen's Printer.

de Raeve (1994). Ethical issues in palliative care research. Palliative Medicine, 8, 298-305.

Department of Health and Social Services (2003). Business Plan 2003-2004 Iqaluit, Nunavut: Government of Nunavut.

Dunn, P. (2001). Terminal illness and Aboriginal people. Palliative Care News, Winter Edition 2001, 7-8.

Ellerby, J. H., McKenzie, J., McKay, S., Gariepy, G. J., & Kaufert, J. M. (2000). Bioethics for clinicians: 18. Aboriginal cultures. CMAJ, 163, 845-850.

Elsay, B. & McIntyre, J. (1996). Assessing a support and learning network for palliative care workers in a country area of South Australia. Aust.J.Rural.Health, 4, 159-164.

Ferris, F. D., Balfour, H. M., Bowen, K., Farley, J., Hardwick, M., Lamontagne, C., Lundy, M., Syme, A., & West, P. (2002). A Model to Guide Hospice Palliative

Care: Based on National Principles and Norms of Practice. Ottawa, Ontario: Canadian Hospice Palliative Care Association.

Finlay, I., McQuillan, R., & Tower, H. (1995). Paediatric palliative care: the role of an adult palliative care service. Palliative Medicine, 9, 166-167.

Fossett, R. (2001). In order to live untroubled: Inuit of the central arctic, 1550-1940. Winnipeg, Manitoba: University of Manitoba Press.

Fountain, A. (1999). Ethnic minorities and palliative care in Derby. Palliative Medicine, 13, 161-162.

Freeman, M., Ramanathan, S., Aitken, A., Dunn, P., & Aird, J. (1998). Rural palliative care volunteer education and support program. Aust.J.Rural.Health, 6, 150-155.

Fried, O. (2000). Providing palliative care for Aboriginal patients. Australian Family Physician, 29, 1035-1038.

Gaffin, J., Hill, D., & Penso, D. (1996). Opening doors: improving access to hospice and specialist palliative care services by members of the black and minority ethnic communities. Commentary on palliative care. Br.J.Cancer Suppl, 29:S51-3., S51-S53.

Garcia, M. Materiel resources for palliative care. 2003.
Ref Type: Personal Communication

Geiger, H. J. (2001). Racial stereotyping and medicine: the need for cultural competence. CMAJ, 164, 1699-1700.

Gibson, R. (2001). Palliative care for the poor and disenfranchised: a view from the Robert Wood Johnson Foundation. Journal of the Royal Society of Medicine, 94, 486-489.

Government of Nunavut. The Bathurst Mandate Pinasuaqtavut. 2000.
Ref Type: Bill/Resolution

Government of Nunavut Communications (2003). Health minister launches telehealth network. website [On-line]. Available:
www.gov.nu.ca/Nunavut/English/news

Health Canada (1999). First Nations and Inuit HOme and Commuity Care Program (FNIHCCP).

Hinton, J. (1994a). Can home care maintain an acceptable quality of life for patients with terminal cancer and their relatives? Palliative Medicine, 8, 183-186.

Hinton, J. (1994b). Which patients with terminal cancer are admitted from home care? Palliative Medicine, 8, 197-210.

Hotson, K., Macdonald, S. M., & Martin, B. D. (1999). Towards improved palliative care in Manitoba: understanding death and dying in First Nations communities. Bachelor of Science in Medicine University of Manitoba.

House, N. (1993). Helping to reach an understanding. Palliative care for people from ethnic minority groups. Professional Nurse, 8, 329-332.

Inuit Tapiriit Kanatami (2002). Discussion paper on end-of-life and palliative care.

Inuit Tapirisat of Canada (1996). The Inuit Tapirisat of Canada: negotiating research relationships in the North. Internet [On-line]. Available: **wgtrr.ocees@mansfield.ox.ac.uk**

Juarez, G., Ferrell, B., & Borneman, T. (1999). Cultural considerations in education for cancer pain management. Journal of Cancer Education, 14, 168-173.

Kaufert, J. M. & O'Neil, J. (1995). Cultural mediation of dying and grieving among native Canadian patients in urban hospitals. In L.A.DeSpelder & A. L. Strickland (Eds.), The path ahead: readings in death and dying. (pp. 60-74). Mountain View, California: Mayfield Publishing Company.

Kaufert, J. M., Putsch, R. W., & Lavalley, M. End-of-life decision making among Aboriginal Canadians: interpretation, mediation and discord in the communication of "bad news". Journal of Palliative Care 15[1], 31-38. 1999.
Ref Type: Journal (Full)

Kaufert, P. L. & Kaufert, J. M. (1984). Methodological and conceptual issues in measuring the long term impact of disability: the experience of poliomyelitis patients in Manitoba. Social Science and Medicine, 19, 609-618.

Macaulay, A. (2002). Mortality in the Kivalliq Region of Nunavut, 1987-1996. Master of Science University of Manitoba.

McFarlane, J. A. & Clements, W. (1998). The Globe and Mail style book: a guide to language and usage. Toronto, Ontario: McClelland & Stewart Inc.

McNamara, B., Martin, K., Waddell, C., & Yuen, K. (1997). Palliative care in a multicultural society: perceptions of health care professionals. Palliative Medicine, 11, 359-367.

Moffatt, M. E. K., O'Neil, J., & Young, T. K. (1990). Keewatin Health Status Assessment Study Winnipeg, Manitoba: University of Manitoba.

Mount, B. M., Cohen, R., MacDonald, N., Bruera, E., & Dudgeon, D. J. (1995). Ethical issues in palliative care research revisited. Palliative Medicine, 9, 165-166.

Mount, B. M. & Seely, J. F. (1999). Palliative medicine and modern technology. CMAJ, 161, 1120-1121.

National Advisory Committee (2000). A guide to end-of-life care for seniors. Ottawa, Ontario: Tri-Co Printing Inc.

Neuberger, J. (1998). Cultural Issues in Palliative Care: Introduction. In D. Doyle, G. W. C. Hanks, & N. MacDonald (Eds.), Oxford Textbook of Palliative Medicine (Second ed., pp. 777-785). Oxford, England: Oxford University Press.

Nunavut Research Institute & Inuit Tapirisat of Canada. Negotiating Research Relationships: A Guide for Communities. 1998. Ottawa, Canada, Inuit Tapirisat of Canada.

Ref Type: Pamphlet

O'Neill, J. & Marconi, K. (2001). Access to palliative care in the USA: why emphasize vulnerable populations? Journal of the Royal Society of Medicine, 94, 452-454.

Palliative Care Australia. Exploring indigenous palliative care. Palliative Care News Winter edition 2001, 1-16. 2001.

Ref Type: Journal (Full)

Prior, D. (2001). Cultural safety in palliative care: issues for research and practice. Palliative Care News, Winter edition 2001, 6.

Romanow, R. J. (2002). Commission on the Future of Health Care in Canada.

Seale, C. (2000). Changing patterns of death and dying. Social Science and Medicine, 51, 917-930.

Seely, J. F., Scott, J. F., & Mount, B. M. (1997). The need for specialized training programs in palliative medicine. CMAJ, 157, 1395-1397.

Statistics Canada (2002). Census recensement 96. Internet [On-line]. Available: www.statcan.ca

Statistics Canada (2003). 2001 Community Profiles. website [On-line]. Available: <http://www.statcan.ca/start.html>

Strang, P. (2000). Qualitative research methods in palliative medicine and palliatvie oncology. Acta Oncologica, 39, 911-917.

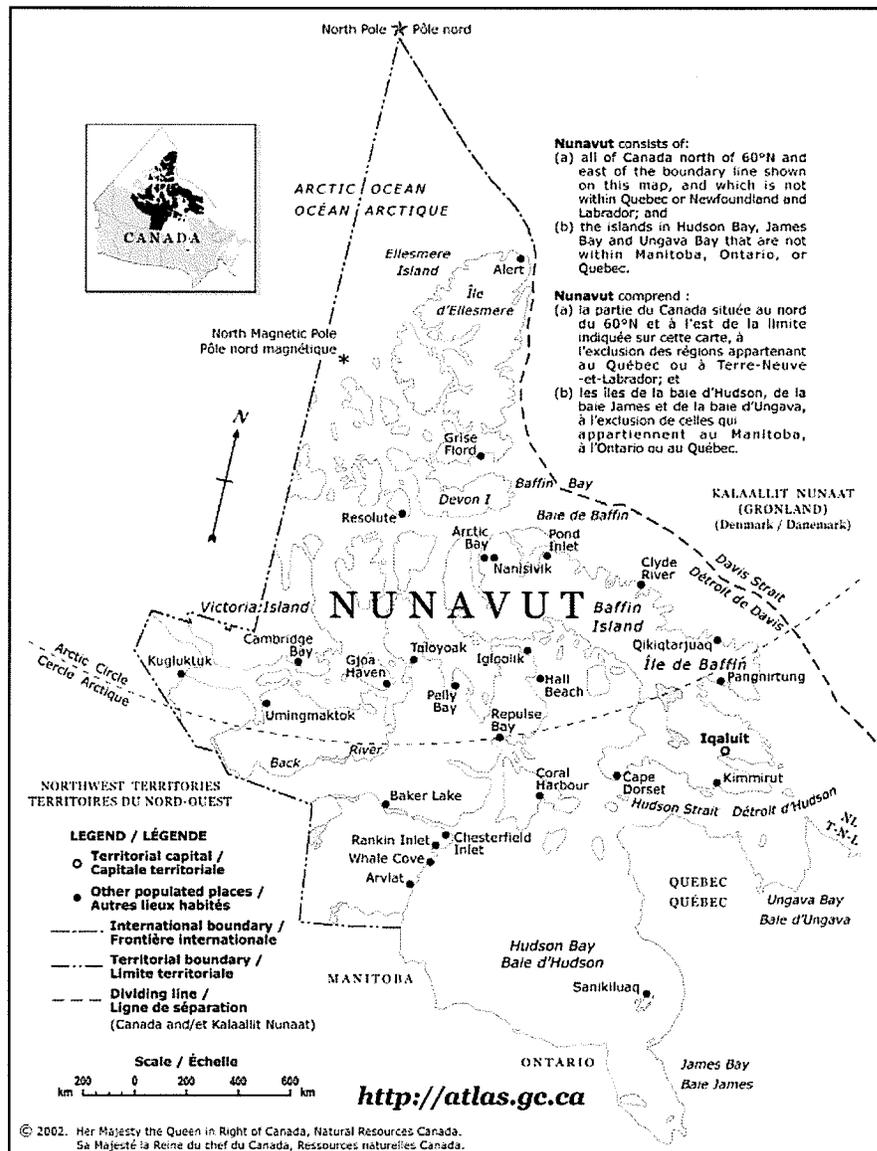
Vastyan, E. A. (1986). Spiritual aspects of the care of cancer patients. CA Cancer J.Clin., 36, 110-114.

Wilkes, L., White, K., & O'Riordan, L. (2000). Empowerment through information: supporting rural families of oncology patients in palliative care. Aust.J.Rural.Health, 8, 41-46.

World Health Organization Expert Committee (1990). Cancer pain relief and palliative care (Rep. No. 804). Geneva: World Health Organization.

Appendices

Appendix A. Map of Nunavut.



The Kivalliq Region of Nunavut is comprised of the five communities on the west coast of Hudson Bay, the inland community of Baker Lake, and Coral Harbour on Southampton Island. The community of Sanikiluaq has been included in the Kivalliq Region in the context of this document, as health services are administered regionally to include this community. Source: Natural Resources Canada; web site <http://atlas.gc.ca>; reproduction is in compliance with Natural Resources' standards for non-commercial use.

Appendix B. The Bathurst Mandate

Government of
Nunavut



The Bathurst Mandate Pinasuaqtavut : that which we've set out to do

Our hopes and plans for Nunavut

The Government of Nunavut has developed this detailed plan with the help and inspiration of many people and organizations across the Territory. The origins of the paper are in the first Cabinet retreat at Kimmirut. Later the ideas were discussed at Baker Lake in June and then finalized in August 1999 at Bathurst Inlet.

"We have listened to your hopes and ideas for the future of Nunavut. We have listened to your expectations of this new Government and to your priorities and needs. This is our plan for the next five years.

These pages include our priorities for Nunavut; Healthy Communities, Simplicity and Unity, Self-reliance and Continuing Learning, and the principles that will guide us. We have outlined specific objectives for the next five years and also looked to the future, creating a vision of Nunavut in the year 2020.

We welcome your views on this plan. Talk to your MLA and let us know your ideas. Over the coming months and years we will report back on the progress we make and review our targets with you.

I am confident that together, we will make a real difference to the everyday lives of Nunavummiut, today and in the future."

Paul Okalik

Premier

Government of Nunavut

Healthy Communities

Simplicity and Unity

Self Reliance

Continuing Learning

Healthy Communities

We believe that:

The health of Nunavut depends on the health of each of its physical, social, economic and cultural communities, and the ability of those communities to serve Nunavummiut in the spirit of *Inuuqatigiittiarniq*; the healthy inter-connection of mind, body, spirit and environment.

Principles that will guide us are:

- People come first;
- People are responsible and accountable for their own well being;
- Nunavut needs to provide options and opportunities which build the strengths of individuals, families and communities;
- We acknowledge and will respond to the challenges of substance abuse, violence and loss as individuals, families and communities;
- Building the capacity of communities will strengthen Nunavut;
- All levels of government working together will strengthen Nunavut.

In 2020, Nunavut is a place where:

- Self assured, caring communities respond to the needs of individuals and families;
- We respect the accumulated wisdom of our elders, examining and evaluating our actions based on the best of both modern knowledge and traditional ways;
- Well informed individuals and communities have the capacity and exercise responsibility for decision making; Nunavummiut own and manage a strong mixed economy where residents have productive choices for economic participation;
- Strong transportation and communication links exist between communities and southern Canada, and increase communities' land and water access;
- Health and social conditions and indicators are at or better than the Canadian average;
- Families and individuals in Nunavut have fair access to a range of affordable housing options;
- The raising and teaching of children and the care of those in need, '*Ilagiinniq*' (kinship) and '*Inuuqatigiinniq*' (community kinship), are a collective community process.
- We enjoy and manage a clean, pristine environment, in our communities and on the land and waters.

Over the next five years, Departmental Business Plans and activities will give priority to completing these objectives:

- Open and maintain a public dialogue on housing issues, while developing and implementing immediate and long-term plans to respond to housing shortfalls as one of the two primary commitments of this government's mandate;
- Evaluate spending on courts and corrections, evaluate alternative program options and put in place long-term plans;
- Develop, with our land claims partners, a new Wildlife Act that recognizes the co-management regime of our resources;

- Recruit, train, and retain Health and Social Services staff at full capacity in all communities and facilities;
- Under the leadership of the departments of Sustainable Development, Community Government and Transportation and Health and Social Services, work with communities to:
 - create within each department of the Government of Nunavut the ability to support community capacity building; and, on a community by community basis:

- create a *Capacity Plan* to develop and support the people, assets and authorities needed to build strength and diversity in each community;
- develop and maintain *Wellness Plans* for each Nunavut community, identifying strengths, gaps and needs.
- create long-term plans to sustain and improve community resources and access for each identified community need;
- create and maintain an *Economic Strategy* for Nunavut.

and move to support and fund communities and programs in a manner consistent with these plans.

- Develop and implement a Nunavut-wide volunteer strategy.

Simplicity and Unity

We believe that:

Simplicity in the processes of government encourages access by all; makes the tasks more focused and more achievable; and invites participation.

Principles that will guide us are:

- Inuit Qaujimajatuqangit will provide the context in which we develop an open, responsive and accountable government;
- By developing programs and services which are fair, understandable and easy to access we will encourage public participation and create accountability;
- Every activity and expense must have a productive purpose;
- Simplicity does not mean uniformity - diversity in approach can build on unique strengths, resources and ways of doing things;
- MLA's will be respected as important sources of community opinion;
- Cooperation will be the operating standard at every level.

In 2020, Nunavut is a place where:

- The Government of Nunavut conducts its business with openness and honesty, encouraging public input;
- The structures and activities of government serve Nunavut's needs, with the most effective use of resources;
- Inuktitut, in all its forms, is the working language of the Government of Nunavut;
- Equal opportunities exist across Nunavut in areas of jobs, education, health, justice and all other services;

- An informed public has taken up the challenges and assumed the responsibilities of active community;
- Communities have seamless access to government officials, information and services.

Over the next five years, Departmental Business Plans and activities will give priority to completing these objectives:

- Remove, consolidate or integrate unnecessary government structures;
- Create a simple, timely and broadly based process for the creation and change of laws, using the forum of a Law Review;
- Allow broad public access to all laws and to government policies, forms and program information in English, French and Inuktitut in all its forms;
- Write and maintain simple and understandable policies for every government department;
- Create a single time zone;
- Recognize the need to support Nunavummiut in each age group to participate in community life and the life of Nunavut;
- Work within the land claim and with claims organizations to best use and share resources in Nunavut, while fulfilling land claims objectives and obligations;
- Develop a Nunavut business incentive policy, with our land claims partners, incorporating all the requirements of Article 24;
- Develop and implement a protocol agreement with Nunavut Tunngavik Incorporated defining common goals and processes;
- Work with others in Nunavut to simplify and enhance access to business support programs.

Self Reliance

We believe that:

As individuals we are each responsible for our own lives and responsible through our own efforts and activities to provide for the needs of our families and communities;
 As communities and as a government we are connected to and reliant on each other to care for those in need, to establish common goals, and to secure the resources required to achieve those goals;
 As Nunavummiut we look to support ourselves and contribute to Canada through the potential of our land, the responsible development of our resources and the contributions of our peoples and our cultures.

Principles that will guide us are:

- We will work within our means;
- We will incorporate traditional activities and values into new strategies to participate actively in the development of our economic resources;
- We will build on our strengths, respecting and highlighting the unique elements of our residents, communities, and the environment and economy in Nunavut;
- Nunavut residents should receive every opportunity to benefit from public dollars spent in and by Nunavut;
- Full and willing commitment to the Nunavut land Claims Agreement will be the standard;

- Nunavut can and will contribute to our country, as a committed and active participant in the life of Canada, and to the circumpolar world as an active Arctic neighbour.

In 2020, Nunavut is a place where:

- The Government of Nunavut meets its obligations under the Nunavut Land Claims Agreement in a spirit of active cooperation;
- There are options for individuals to achieve personal growth within Nunavut communities;
- Nunavummiut are active in taking up an increasing number of economic opportunities and have low levels of dependency on government;
- An informed society is making decisions for self, family and community;
- Access to programs and services are seamless; straightforward, understandable and efficient;
- Nunavut enjoys growing prosperity while remaining debt-free;
- Nunavut is an active and respected contributor, nationally and internationally.

Over the next five years, Departmental Business Plans and activities will give priority to completing these objectives:

- Conduct a review of Income Support and related issues to find common commitments, then implement a revised program, putting in place incentives for individuals and families to achieve self-reliance;
- Fulfill the commitments of government to deliver employment to decentralized communities;
- Working with the Nunavut Association of Municipalities, create new municipal legislation that will respond to the need for local options and opportunities for governance;
- Develop and implement monitoring and evaluation systems for Government of Nunavut programs at all levels;
- Build local employment and strengthen and support local businesses and organizations while promoting effective competition;
- Conclude agreements with the Government of Canada for public investment in key infrastructure (connectivity, roads, wharves, geoscience, mapping);
- Bring to Nunavut, or review and re-negotiate, all government functions contracted to the Government of the NWT on April 1, 1999;
- Commence negotiations and work towards agreements with the Government of Canada to assure Nunavut of a fair share of the resources of its lands and waters and to govern allocations and royalty regimes;
- Work to allow Nunavut to take its place and develop its role as an active, articulate, patient and conciliatory partner within Canada and the circumpolar world;
- Build an effective, functional and skilled public service, which is responsive to the public it serves and increasingly representative of the population of Nunavut.

Continuing Learning

We believe that:

To achieve the dreams of Nunavut we all need to listen closely and learn well in order to acquire the skills we need to increase our independence and prosperity.

Principles that will guide us are:

- The value of teaching and learning shall be acknowledged at all levels and from sources inside and outside of our communities;
- Learning is a lifelong process;
- Equal opportunity and equal access across Nunavut is fundamental to our success;
- It is important to recognize all of the potential teachers in our communities, beginning with elders and in families;
- Land and language skills and respectful pride in our cultures and languages are fundamental for adults and children;
- Our education system needs to be built within the context of Inuit Qaujimajatuqangit;
- Respect for individuals is the basis of effective learning and a healthy workplace.

In 2020, Nunavut is a place where:

- Our population is adaptable to change and welcomes new skills, while preserving its culture, values and language of origin;
- We are a fully functional bilingual society, in Inuktitut and English, respectful and committed to the needs and rights of French speakers, with a growing ability to participate in French;
- We have a representative workforce in all sectors;
- Educational programs are offered on a strategic basis, based on community by community needs;
- There is a full range of interlocking educational programs allowing individuals continued access throughout spectrum;
- Inuit professionals of all kinds have been supported in their training and have taken leadership roles in our communities;
- Our history and accomplishments have been preserved and recognized in books and artworks, in recorded stories, in places of learning, and in common knowledge of our people. We are a source of pride to all Canadians;
- In our areas of strength, we have assumed a leadership role in Canada and have looked beyond Nunavut to give and receive inspiration and support, and to lead an active exchange of ideas and information.

Over the next five years, Departmental Business Plans and activities will give priority to completing these objectives:

- A government-wide effort to support training and learning for a Nunavut-based workforce as one of the two primary commitments of this government's mandate;
- Train more elementary and high school teachers in Nunavut;
- Train nurses in Nunavut;
- Provide educational programs for a wide range of health and social services providers
- Improve student/teacher ratios Nunavut-wide;
- Train in Nunavut for all the trades;
- Respond to the generation of passive speakers of Inuktitut in all its forms;
- View every element of the government budget as a potential training budget;
- Graduate more students from school, college and universities;
- Under the leadership of the departments of Human Resources and Culture, Language, Elders and Youth, every department will develop and implement, for current and future employees:

- a strategy to support the Inuit Employment Plan;
 - a strategy for on-the-job training and mentoring;
 - a Nunavut orientation and language skills program;
-
- o Increase opportunities in Nunavut for post-secondary learning;
 - o Begin the re-writing of the K-12 school curriculum, to emphasize cultural relevance and academic excellence, to be completed over the next 10 years;
 - o Support and improve the teaching and learning of Inuktitut in all its forms, and the teaching of language generally, in our schools;
 - o Put into place strategies to develop Nunavummiut in every profession as part of a resident workforce.

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Appendix C. Community Information Sheet

Palliative Care and the Kivalliq Region of Nunavut: Determinants of Programme Development and Implementation

Community Information Sheet

Purpose of Study

This research is being conducted to study the features that would assist in the development and implementation of a palliative care programme for the Kivalliq Region of Nunavut. Palliative care is a term used to describe the active total care provided to an individual whose health condition is no longer responding to curative treatment.

Participants in the study will include nurses and other health providers in the communities, administrative staff of the Department of Health and Social Services, patients receiving palliative care, and family members of patients who have received palliative care. The study will be conducted using survey questionnaires and interviews of participants. The study will take place over a period of six months in 2003. The results of the study will be provided to the Department of Health and Social Services, and information will be shared with communities in written form and by presentations in the community if requested.

The University of Manitoba Health Research Ethics Board and Nunavummi Qaujisaqtulirijikkut (Nunavut Research Institute) have approved this research study.

If you wish to participate in the study please contact one of the investigators.

Principal Investigator:

Bruce D. Martin
T162-770 Bannatyne Avenue
Winnipeg, Manitoba
R3E 0W3

e-mail: bmartin@cc.umanitoba.ca

Co-Investigator:

Dr. J. Kaufert
Department of Community Health
Sciences
Faculty of Medicine
University of Manitoba
S113C Medical Services Building
770 Bannatyne Avenue
Winnipeg, Manitoba
R3E 0W3

Appendix D. Participant Information and Interview Consent Form

**Department of Community Health Sciences
Faculty of Medicine
University of Manitoba**

**Palliative Care and the Kivalliq Region of Nunavut:
Determinants of Programme Development and Implementation**

Participant Information and Interview Consent Form

Title of Study:

**Palliative Care and the Kivalliq Region of Nunavut:
Determinants of Programme Development and Implementation.**

Protocol number: "H2003:041"

Principal Investigator:

Bruce D. Martin
T162-770 Bannatyne Avenue
Winnipeg, Manitoba
R3E 0W3

Co-Investigator:

Dr. J. Kaufert
Department of Community Health
Sciences
Faculty of Medicine
University of Manitoba
S113C Medical Services Building
770 Bannatyne Avenue
Winnipeg, Manitoba
R3E 0W3

Note: This research is being conducted by the principal investigator in partial fulfillment of the requirements for the Degree of Master of Science.

Sponsor:

Department of Community Health Sciences
Faculty of Medicine
University of Manitoba

You are being asked to participate in a research study. Please take your time to review this consent form and discuss any questions you may have with the study staff. You may take your time to make your decision about participating in this research study and you may discuss it with your colleagues, friends and family before you make your decision. This consent form may contain words that you do not understand. Please ask the study staff to explain any words or information that you do not clearly understand.

Purpose of Study

This research study is being conducted to study the features that would assist in the development and implementation of a palliative care programme for the Kivalliq Region of Nunavut. Palliative care is a term used to describe the active total care provided to an individual whose health condition is no longer responding to medical treatment. You are being asked to take part in this study because you have direct involvement in issues regarding palliative care, either as a health care provider, or as a recipient of care, or a support person to such a patient. A total of approximately 50 participants will participate in this study over a period of six months.

Study procedures

If you take part in this study, you will have an opportunity to participate in a personal interview with the principal investigator. Your personal time commitment would not exceed two hours. You can stop participating at any time. However, if you decide to stop participating in the study, we encourage you to talk to the study staff.

Risks and Discomforts

No harm should come to you for answering or not answering these questions. We do not think the questions will be difficult to answer. This study is about end-of-life care, a subject that can be difficult to talk about. If you become upset - please talk to a good friend, a family member, a community nurse or any other person who you feel can help you. If you experience emotional distress following participation in this study, you may also call the principal researcher to talk about your feelings. These concerns will not be recorded.

Benefits

By participating in this study, you will be providing information to the principal investigator that may assist in the development of a palliative care programme for the Kivalliq Region. There may or may not be direct benefit to you from participating in this study. We hope the information learned from this study will benefit other members of your community in the future.

Costs

There will be no cost for you to participate in his study.

Payment for participation

You will receive no payment or reimbursement for any expenses related to participating in this study.

Alternatives

If you are a patient, or family member of a patient, you do not have to participate in this for medical or nursing care to be continued now, or in the future.

Confidentiality

Information gathered in this research study may be published or presented in public forums, however your name and other personal identifying information will not be used or revealed. If you are a patient your specific medical condition will not be revealed. The community from which you come will not be identified by name. Absolute confidentiality cannot be guaranteed, however, as your comments may be identifiable simply because of the small number of individuals who are directly involved as consumers of care, providers or administrators in the relatively small study area.

The University of Manitoba Health Research Ethics Board may review research-related records for quality assurance purposes.

If you are a patient, your community physician or medical specialist will not be advised regarding your participation or non-participation in this study.

Voluntary Participation/Withdrawal from the Study

Your decision to take part in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time. Your decision not to participate or to withdraw from the study will not affect your care or that provided to others.

Medical Care for Injury Related to the Study

In the most unlikely case of illness resulting from this study, necessary medical treatment will be available at no additional cost to you.

Questions

You are free to ask any questions that you may have about your rights as a research participant. If any questions come up during or after the study, contact the principal investigator:

Bruce D. Martin
T162-770 Bannatyne Avenue
Winnipeg, Manitoba
R3E 0W3

For questions about your rights as a research participant, you may contact The University of Manitoba Health Research Ethics Board at (204) 789-3389.

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

Statement of Consent

I have read this consent form. I have had the opportunity to discuss this research study with Bruce Martin and/or his study staff. I have had my questions answered by them in language I understand. The risks and benefits have been explained to me. I understand that I will be given a copy of this consent form after signing it. I understand that my participation in this research study is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.

I understand that information regarding my personal identity will be kept confidential, but that confidentiality is not guaranteed.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

Participant signature

Date

Participant printed name

Witness printed name

Interpretation Assistance: If the understanding of this consent process has been aided with the assistance of an interpreter:

Interpreter's Signature

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent

Signature

Date

Bruce D. Martin
Principal Investigator

Appendix E. Nunavut Research Licence

Nunavummi Qaujisaqtulirijikkut / Nunavut Research Institute

Box 1720, Iqaluit, NT X0A 0H0 phone:(867) 979-4108 fax: (867) 979-4681 e-mail: slcnri@nunanet.com

SCIENTIFIC RESEARCH LICENCE

LICENCE # 0301003N-A

ISSUED TO: Bruce Martin
Faculty of Medicine
University of Manitoba
T162-770 Bannatyne Avenue
Winnipeg, Manitoba
R3E 0W3 Canada

TEAM MEMBERS: B. Martin

AFFILIATION: University of Manitoba

TITLE: Palliative Care and the Kivalliq Region of Nunavut: Determinants of Programme Development and Implementation

OBJECTIVES OF RESEARCH:

The ultimate objective of this study is to identify the broad determinants of palliative care programme development and implementation in the Kivalliq Region of Nunavut. This objective will be achieved in the following dimensions: 1. Conduct a survey of the literature regarding specific emphasis on cross-cultural and remote settings; 2. Identify the broad determinants for current and sustained palliative care programming; 3. Identify the requisite supports for palliative care by conducting an environmental scan of the current health and social services system with a Nunavut-specific focus; 4. Identify Canadian Inuit beliefs on death and dying by reviewing existing literature, and supplementing this with information from key informants; 5. Conduct focused interviews of patients and family "units of care" regarding end of life care from both a cultural and needs-based perspective; and 6. Conduct surveys and interviews of health and social service providers to gain their perspective on palliative care programme development and implementation.

DATA COLLECTION IN NU:

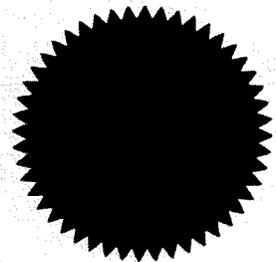
DATES: April 01, 2003-October 01, 2003

LOCATION: Kivalliq - All Communities

Scientific Research Licence 0301003N-A expires on December 31, 2003.

Issued at Iqaluit, NU on July 07, 2003.

 Bruce Rigby
Science Advisor



Appendix F. Interview Protocols: Themes Guiding the Interview

1. Interview Protocol - Family Member or Member of 'Unit of Care'

What comforts did you have in having your family member:

At home?

In home community?

What fears did you have in having your family member:

At home?

In home community?

What needs were well met?

By whom?

What needs could have been better met?

By whom?

How do you interpret the term "palliative care"?

Are you aware of any beliefs or customs specific to the Inuit and/or the Inuit of your community that would be important for health and social service providers to be aware of?

2. Interview Protocol - Health Care Provider

Can you explain what your role is in the provision of end-of-life care?

How do you interpret the term “palliative care”?

Can you identify the education that may have provided you with the skills or comforts to provide palliative care?

What challenges you the most in the provision palliative care, and what do you do to address those challenges?

What resources come from the community to assist you in the role that you have?

How do you feel you are accepted by patients and family members in your current role with regards to palliative care?

Are you aware of any beliefs or customs specific to the Inuit and/or the Inuit of the community in which you work that would be important for health and social service providers to be aware of?

3. Interview Protocol - Health Administrator or Policy Maker

What is the current extent of palliative care programming in the Kivalliq Region?

How would you see palliative care programmes expand/be enhanced?

What benefits would occur if programmes were to be expanded/enhanced

To patients?

To family members?

To health and social services providers?

To the health care system?

What current strengths exist to support expanded/enhanced palliative care?

What barriers exist to enhanced and sustained palliative care programmes?

What could be done to overcome those barriers?

Appendix G. Interview Tracking Document

Palliative Care and the Kivalliq Region of Nunavut: Determinants of Programme Development and Implementation.

Interview Tracking Document

Interview Date: _____ Community: _____

Interview Location: _____

Informant Category:

- Family Member or member of 'Unit of Care'
- Health Care Provider:
Specify by profession: _____
- Health Administrator or Policy Maker

Informant name: _____

If family member, diagnosis of patient that had received palliative care:

Interpreter name: _____

Comments:

Number of Tapes: _____ Approx. Time: _____ min

Transcribed by: _____ Transcription Date: _____

Appendix H. Participant Information and Questionnaire Consent Form

**Department of Community Health Sciences
Faculty of Medicine
University of Manitoba**

Palliative Care and the Kivalliq Region of Nunavut: Determinants of Programme Development and Implementation

You are invited to take part in a research study that will review the aspects that would assist in the development and implementation of a palliative care programme for the Kivalliq Region of Nunavut. Palliative care is a term used to describe the active total care provided to an individual whose health condition is no longer responding to medical treatment. You are being asked to take part in this study because you have direct involvement in issues regarding palliative care. A total of approximately 50 participants will participate in this study over a period of six months.

Bruce D. Martin is conducting the study in partial fulfillment of the requirements for the Degree of Master of Science. The co-investigator and thesis advisor is Dr. J. Kaufert, Department of Community Health Sciences, Faculty of Medicine, University of Manitoba. The Health Research Ethics Board of the Bannatyne Campus Research Ethics Board, University of Manitoba, and Nunavummi Qaujisaqtulirijikkut (Nunavut Research Institute) have approved the study.

You are being asked to fill out one short questionnaire. This will take about 20 minutes. This is our only request of you. With your help, we will learn more about end-of-life care needs in the Kivalliq Region. Although you probably will not benefit directly from this study, you will help to potentially improve end-of-life care in Kivalliq specifically and Nunavut in general.

You do not have to fill out a questionnaire and you don't need to answer every question. We are not asking for your name or any other specific information that could identify you. If you wish to use your name you may do so, however your name and other identifying information will not be used or revealed. The information obtained from your questionnaire will be entered into a database. The information you give us will be added to other information gathered in this study. Information gathered in this research study may be published or presented in public forums, however identifying information will not be used or revealed.

No harm should come to you for answering or not answering these questions. We do not think the questions will be difficult to answer. As this study is about end-of-life care, a subject that can be difficult to talk about, the questionnaire may bring up thoughts that cause an emotional response. If you become upset, please talk to a good friend, a colleague, or another person who can help you. You can also call the principal investigator or co-investigator to talk about your feelings. No details will be recorded if you make a call.

Principal Investigator:

Bruce D. Martin
T162-770 Bannatyne Avenue
Winnipeg, Manitoba
R3E 0W3

Co-Investigator:

Dr. J. Kaufert
Department of Community Health
Sciences
Faculty of Medicine
University of Manitoba
S113C Medical Services Building
770 Bannatyne Avenue
Winnipeg, Manitoba
R3E 0W3

For questions about your rights as a research participant, you may contact The University of Manitoba Health Research Ethics Board at (

You are encouraged to keep this consent form for your personal records.

Protocol number: "H2003:041"

**Palliative Care and the Kivalliq Region of Nunavut:
Determinants of Programme Development and Implementation
Questionnaire**

I have read and understand the “Participant Information and Questionnaire Consent Form” and I am voluntarily completing the Questionnaire.

1. Age: _____

2. Sex: F M

3. What is your current profession? Please check ().

<input type="checkbox"/>	Clerk Interpreter	<input type="checkbox"/>	Registered Nurse, DHSS, H&CC
<input type="checkbox"/>	Community Health Representative	<input type="checkbox"/>	Registered Nurse, DHSS Public Health
<input type="checkbox"/>	Community Mental Health Worker	<input type="checkbox"/>	Registered Nurse, Agency
<input type="checkbox"/>	Health or Social Services Administrator	<input type="checkbox"/>	Registered Psychiatric Nurse
<input type="checkbox"/>	Home Care Aide	<input type="checkbox"/>	Rehabilitation Therapist, OT
<input type="checkbox"/>	Minister, priest or pastor	<input type="checkbox"/>	Rehabilitation Therapist, PT
<input type="checkbox"/>	Physician, full-time	<input type="checkbox"/>	Social Worker
<input type="checkbox"/>	Physician, locum	<input type="checkbox"/>	Other: (please identify)
<input type="checkbox"/>	Registered Nurse, DHSS, full time	<input type="checkbox"/>	
<input type="checkbox"/>	Registered Nurse, DHSS, relief		

4. How many years have you been in your current profession? _____ year(s)

5. How many years have you been working in remote communities? _____ year(s)

6. How long have you been working in your current position? _____ year(s)

7. Have you been involved in providing palliative care in remote communities?

Yes No

If Yes, please continue with this question. If No, please go to question 8.
How many palliative care patients have you been involved with in remote communities in the past:

one year? _____

five years? _____

What has been the primary diagnosis for those palliative care patients?

What other diseases have been involved? Please check (✓) those that apply.

<input type="checkbox"/>	Cancer	<input type="checkbox"/>	HIV/AIDS	<input type="checkbox"/>	Renal failure
<input type="checkbox"/>	Respiratory disease	<input type="checkbox"/>	Cardiovascular disease	<input type="checkbox"/>	Cerebrovascular disease
Other: (please specify)					

8. Did you receive any palliative care training as a student in your current profession?

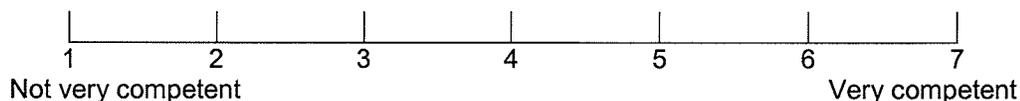
Yes No

9. Have you received any palliative care training since completing education in your current profession? If so please describe (i.e. type of course, duration, location).

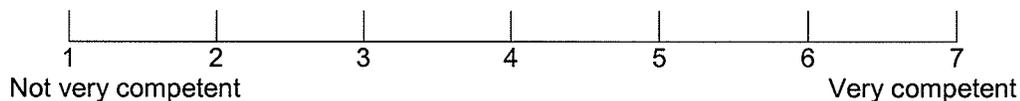
10. Would you participate in palliative care education in the future? Yes No

If Yes, where would you prefer to access the education?

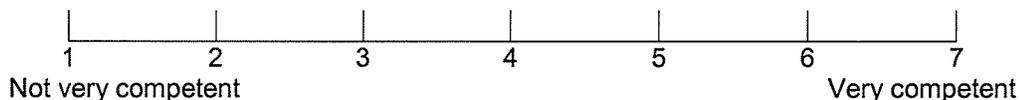
11. How competent do you feel in providing palliative care in your community?



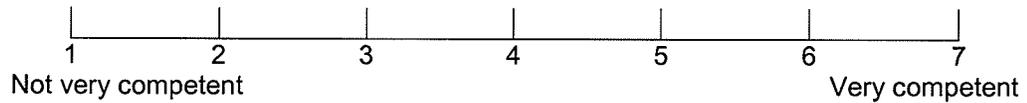
12. How competent do you feel in managing or supporting palliative care patients with pain?



13. How competent do you feel in managing or supporting palliative care patients with other symptoms (shortness of breath, nausea, weakness)?



14. How competent do you feel in managing or supporting palliative care patients with depression or anxiety?



15. How competent do you feel in addressing palliative care from a cultural perspective?



16. Are you aware of culturally determined beliefs amongst the Inuit regarding death, dying, or bereavement? Yes No

If Yes, could you please identify what these beliefs might include? (If detailed, please append your comments at the end of the questionnaire.)

17. In your opinion, where would most palliative care patients of the Kivalliq Region choose to die?

18. In your opinion, where do these patients actually tend to die today?

19. Would it be a fair statement to say that death from chronic illness has become progressively more removed from the community over the past few decades?

Yes No Unsure

20. In your opinion, do you think the community would be accepting of increased palliative care provision in the community?

Yes No Unsure

21. In your opinion, what might be the potential barriers to increasing the amount of palliative care that could be provided in the community?

Please list as many as come to mind.

22. In your opinion, what changes could be made to the Health Centre or the administration of services that might allow for more palliative care services to be provided in the community?

Please list as many as come to mind.

23. Please identify any other comments that you wish to share with the researchers.

You do not have to sign this questionnaire, or otherwise identify yourself.

**Thank you for contributing to this research study.
The questionnaire may be returned in the stamped and self-addressed
envelope provided.**

Appendix I. Community Survey of Resources for the Provision of Palliative Care

Palliative Care and the Kivalliq Region of Nunavut: Determinants of Programme Development and Implementation.

Community Survey of Resources for the Provision of Palliative Care

Thank you for assisting with this survey to determine what resources are present in your community to aid in the provision of palliative care.

When completing the form, please note the following:

- The definition of Palliative Care for the purpose of this study is *the active total care of patients whose disease is not responsive to curative treatment*. The study is therefore not confined to the management of individuals with a diagnosis of cancer.
- Resources have been broadly defined in the following three categories:
 - human resources:
 - Health and Social Services staff (Please identify the *human resources* anticipated as of July 1, 2003.)
 - Other
 - facility resources
 - materiel resources (Equipment and supplies that are in the community that could be made available for palliative care programming.)

If you have any additional comments, please attach them to this document.

If any questions arise, please do not hesitate to contact me:

or

Thanks

Bruce D. Martin

Community: _____

A. Human Resources – Health and Social Services

Position	Positions filled July 1, 2003	Positions vacant July 1, 2003
Clerk Interpreter		
Community Health Representative		
Community Mental Health Worker		
Home Care Aide		
Registered Nurse, CHN		
Registered Nurse, H&CC		
Registered Nurse, Public Health		
Registered Psychiatric Nurse		
Rehabilitation Therapist, OT		
Rehabilitation Therapist, PT		
Social Worker		
Other: (please identify)		

Note: If part-time, please identify, i.e. 0.5, etc.

A. Human Resources – Other

Position	Number of Individuals
Specific community elders who become actively involved	
Minister, priest or pastor	
Other: (please identify)	

B. Facility Resources

Type of Facility	√
Hospice	
Elder's Facility	
Other facility for short-term stay:	
Other (please identify):	

C. Materiel Resources (Equipment and supplies that are in the community that could be made available for palliative care programming.)

Resource	√
Commode chair	
Hospital bed	
Hoya lift	
Oxygen concentrator	
Palliative care medication kit	
Portable subcutaneous infusion pump	
Other (please identify):	

Date: _____ Information provided by: _____

If you have additional comments, please attach them to this document.

Please fax the completed form to: Bruce D. Martin 204-284-9877 (home) or 204-774-8919 (office).

Appendix J. Community Survey of Patients Having Received Palliative Care

Palliative Care and the Kivalliq Region of Nunavut: Determinants of Programme Development and Implementation. Community Survey of Patients Having Received Palliative Care

Thank you for assisting with this aspect of data collection for the above named study.

It is hoped that the past five to ten year's experience can be reviewed. Please provide information *to the best of your knowledge*. If you have only recently arrived in the community please do not hesitate to seek information from those who can assist (i.e. CHR, clerk interpreter).

When completing the form, please note the following:

- Age: can be approximate if actual age is not available
- Diagnosis: the definition of Palliative Care for the purpose of this study is *the active total care of patients whose disease is not responsive to curative treatment*. The study is therefore not confined to the management of individuals with a diagnosis of cancer.
- Duration of Palliative Care: identify an approximate number of months of care; if this is not readily available, give a subjective value of 'short', 'medium' or 'long-term'.
- Year of Death: approximate year is acceptable; if currently receiving palliative care, please identify.
- Place of Death: if applicable, identify place of death (i.e. home, Churchill, Winnipeg, other).

Do **not** identify the patient by name.

The community name **will not** be identified in the final report.

If you wish to make specific comments regarding any of the cases, please identify the case by number and attach your comments on an additional page.
This form can be photocopied if required for additional cases.

If any questions arise, please do not hesitate to contact me:

Thanks

Bruce D. Martin

Community Survey of Patients Having Received Palliative Care

Community: _____ Information provided by: _____

	Gender	~Age	Diagnosis	Duration of Palliative Care	Year of death or currently receiving care	Place of Death or current location of care

Details for completing this form are on the accompanying letter.