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PERSON-CENTRED PALLIATIVE CARE: A FIRST NATIONS PERSPECTIVE

PERSON-CENTRED PALLIATIVE CARE: A FIRST NATIONS PERSPECTIVE

BY VALERIE O'BRIEN, B.A.

A Thesis Submitted to the School of Graduate Studies

in Partial Fulfillment of the Requirements for the Degree

Master of Science

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MASTER OF SCIENCE (2012) McMaster University
(Health Research Methodology) Hamilton, Ontario

TITLE: Person-Centred Palliative Care: A First Nations Perspective

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Pages: ix, 117

Abstract

Introduction: Palliative care in Canada is an under-funded service for all Canadians, but for Aboriginal people in Canada, the level of access to such care is significantly lower. This study examined the system of palliative care delivery at Six Nations of the Grand River. The overall aim of the project was to identify ways on how the system of care could be improved.

Methods: A qualitative case study approach was used. Interviews were held with Elders and family caregivers to identify the priorities in care delivery from their perspective. Focus groups were held with representatives from palliative care service provider agencies in an effort to identify the strengths and challenges within the system and to determine how palliative care services provided to the members of Six Nations could be improved.

Findings: Themes identified in the interviews included: personable, caring care; culturally-competent care; open two-way communication; support for family caregivers; palliative home care should be available; meeting comfort needs of the person; and the need for a hospice in the community. The main theme identified in the focus groups with care providers included: relationship/rapport issues between provider organizations; within-program strengths and challenges; cultural considerations in care; and broader system factors that influence care.

Discussion: Relationship/rapport issues were identified as a challenge, and it appeared that the focus groups provided an opportunity for communication between the organizations to improve. Identification of within-program challenges – and ways to

address these challenges - may provide opportunities for each organization to improve how palliative care services are delivered at Six Nations. Identification of broader system factors that influence care may also benefit patients in need of palliative care.

Acknowledgments

I must first acknowledge the Elders, family caregivers and Six Nations health care providers who shared their time, insight and experiences with me on this project. I acknowledge the significant contributions of Lori Monture, Manager of the Six Nations Long Term Care/Home & Community Care program, who I considered my "community partner" throughout this process. This project would not have happened without your support. Thank you.

I express my appreciation to my thesis supervisor, Dr. Kevin Brazil, for his patient support and guidance throughout this project. I also express my thanks to Dr. Harriet MacMillan and Dr. Lynne Lohfeld, my thesis committee members, for their expert advice and guidance.

I acknowledge the Indigenous Health Research Development Program for the support I received over the years, and my supervisors, Dr. Wayne Warry and Dr. Dawn Martin-Hill, for their support and words of encouragement.

And last but not least, I acknowledge the support of my husband, Don, and all my family for their support throughout this process.

Table of Contents

ABSTRACT iii
ACKNOWLEDGMENTS v
TABLE OF CONTENTS vi
LIST OF TABLES viii
GLOSSARY AND ABBREVIATIONS ix
CHAPTER ONE: INTRODUCTION 1
Palliative Care definition 2
Palliative Care in Canada 2
Six Nations of the Grand River – Community Description 3
Community Engagement 5
Researcher Profile 5
Research Capacity Development 6
Jurisdiction Issues 6
Rationale for study 8
Research Questions 9
Outline of the Thesis 10
CHAPTER TWO: LITERATURE REVIEW 11
Framework for Conducting PC Research in FN Communities 12
Northwestern Ontario "remote" experiences 13
Aboriginal PC in other parts of Canada 15
PC for Aboriginal People in Australia, New Zealand and the US 17
Medicine Wheel Teachings and PC 20
Appropriate Community Engagement Strategies in PC Research 20
National Strategies Addressing Aboriginal PC Issues in Canada 20
Summary 22
CHAPTER THREE: METHODS 24
Research Approach 24
Interpretive Inquiry 25
Data Sources 25
Methods and Underlying Principles 26
Trustworthiness 29
Recruitment and Sample 30
Data Collection Instruments and Processes 33
Designing the Interview Guides 33
Analysis of Elder and Family Caregiver Interviews 36
Analysis Framework 37
Interpretive Process 37
Initial Approach to Analysis 38
Focus Group Data Analysis 40
Ethical Considerations 41
Presentation of Findings 42

Table of Contents Continued

CHAPTER FOUR: FINDINGS 43
Study Participants 43
Phase I Interviews 45
Elder Interviews 45
Important Aspects of Care Identified by Elders 53
Summary of Elder Interviews 55
Family Caregiver Interviews 56
Important Aspects of Care Identified by Family Caregivers 63
Summary of Family Caregiver Interviews 65
Elder and Family Caregiver themes and subthemes 67
Palliative Care Provider Focus Group Analysis 69
Relationships and Rapport 69
Communication 70
Lack of Clarity on Roles 71
Jurisdiction Issues 73
Relationship Building 75
Within-Program Strengths and Challenges 76
Brant Community Care Access Centre 76
Six Nations Long Term Care/Home & Community Care 78
Care Partners/First Nations Nursing 81
Cultural Considerations in Providing Care 85
Broader System Factors that Influence Care 86
CHAPTER FIVE: DISCUSSION 88
HNHB Hospice Palliative Care Network 92
Shared Care Model of Palliative Care 94
Study Strengths and Limitations 97
Future Avenues of Research 98
Conclusions 99
REFERENCES 101
APPENDIX A – Ethics approval letters 108
APPENDIX B – Recruitment letter 110
APPENDIX C – Interview Guide 111
APPENDIX D – Focus Group Interview Guide 113
APPENDIX E – Focus Group handout on levels of care 114
APPENDIX F – Information sheet/consent form 115

LIST OF TABLES

Table 1 Important aspects of care – Themes Identified by Elders

Table 2 Important aspects of care – Themes Identified by Family Caregivers

Table 3 Themes by interviewee group

Table 4 Important Aspects of Care at Six Nations
(Elder and Family Caregiver themes and subthemes)

GLOSSARY AND ABBREVIATIONS

Aboriginal Hospice Palliative Care	AHPC
Brant region Community Care Access Centre	CCAC
Care Partners/First Nations Nursing	CP/FNN
First Nation	FN
Hamilton Niagara Haldimand Brant region	HNHB
(one of 14 LHIN regions: Six Nations is located in this region)	
Haudenosaunee, Longhouse people	People of Six Nations
Hospice Palliative Care Network	HPCN
Local Health Integration Network	LHIN
Palliative Care	PC
Six Nations Long Term Care/Home & Community Care	SN LTC/HCC

Chapter One: Introduction

Aboriginal people in Canada suffer both higher rates of chronic disease and the complications arising from them at younger ages than the general Canadian population. (Adelson, 2005, S56) The rates of non-insulin-dependent diabetes mellitus in the Aboriginal population are three to five times the national average, five percent of First Nations people develop the disease by the time they reach their 30's, with the rate rapidly increasing with age. (Adelson, 2005, S56) Young, et al. (2000) report that the long-term complications of diabetes affecting the cardiovascular system, eyes, kidneys and nerves result in premature death, disability and a compromised quality of life all of which are of public health significance. The rates of other chronic diseases are also of concern. Reading (2009) cites several studies that demonstrate higher rates of cardiovascular disease (p. 88-9), tuberculosis (p. 91), and an increasing rate of cancer among Aboriginal peoples with significantly lower survival rates for some cancers (p. 108).

The need for appropriate palliative care services for Aboriginal people is urgent, particularly with the number of Aboriginal people 65 and over expected to double between 2001 and 2017. (Statistics, Canada, 2005. http://www.statcan.gc.ca/pub/91-547-x/91-547-x2005001-eng.pdf), p.9

Prince and Kelley (2006) report that: "Geographical and cultural barriers affect how health care is delivered to First Nations communities. As a result, palliative care programs in First Nations communities are virtually non-existent." (p. 8)

They also cite Hotson, MacDonald and Martin (2004) who report it is widely believed by both Aboriginal people and health care providers that the majority of Aboriginal people living in remote First Nations would prefer to die at home. Despite this, many palliative patients are referred to larger urban centres for palliative treatment, and often die in urban hospitals far from their family and friends.

Palliative Care definition

In this thesis, I have adopted the World Health Organization definition of palliative care which states that: "Palliative care improves the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement." (http://www.who.int/cancer/palliative/en/)

Palliative Care in Canada

Palliative Care in Canada as a whole is an under-funded service, with the availability of care not meeting the needs of Canadians. The Parliamentary Committee on Palliative and Compassionate Care, "Not to be Forgotten: Care of Vulnerable Canadians" (2011) reports: "Canada still falls far short of quality end-of-life care for all, with only 16-30% of those who need it receiving palliative care." (p. 7)

Statistics on palliative care service provision at Six Nations and other First Nations are not available, though it is reported that the majority of First Nations do not have access to the same level of health care services as the rest of Canadians (Kelley, 5).

The Parliamentary Committee on Palliative and Compassionate Care (2011) report included six recommendations on ways to improve palliative care services in Canada. Recommendation #5 states:

> We call upon the federal government to strengthen the home care delivery program for First Nations, Métis and Inuit communities, developing home delivered palliative care resources, sensitive to community, cultural, familial and spiritual needs. Research, training, and capacity building, are required for First Nations, Métis and Inuit peoples to receive the high quality palliative and end-of-life care they deserve. (p. 39)

Though the majority of First Nations in Canada do not have palliative care programs in place, one First Nations community located in Southern Ontario, Six Nations of the Grand River, does provide palliative care services. This provides the opportunity to examine how one First Nation's palliative care system works, what its strengths and challenges are and to determine how the system can be improved.

Six Nations of the Grand River - Community description

The community of Six Nations of the Grand River is comprised of 6 different tribes: Mohawk, Cayuga, Onondaga, Oneida, Seneca, and Tuscarora. The traditional peoples refer to themselves as Haudenosaunee, and often, as "longhouse people" in reference to the type of housing and communal living spaces used by the Haudenosaunee.

Six Nations of the Grand River is the largest First Nation in Canada with an on-reserve population of over 11,000 people. The large on-reserve population allows for the

existence of a highly-structured health service delivery system that includes an ambulance service, a birthing centre, a long-term care facility, a health services centre that provides primary care services delivered by a family health team, and a long term care/home and community care program. The community also has its own police force, child protection agency, and women's shelter.

The unique system of palliative care that is currently in place is a mix of services offered on-reserve through the Six Nations Long Term Care/Home & Community Care Program (LTC/HCC), the Brant Community Care Access Centre (CCAC), and a private nursing company, First Nations Nursing, operated by Care Partners. Care Partners, a private Ontario-based nursing services provider, acquired First Nations Nursing in late 2008, assuming responsibility for all existing local staff. The existence of an on-reserve private nursing organization staffed by mainly Aboriginal nurses makes this a unique system of care.

The First Nations and Inuit Home & Community Care program, established in 1999, is a federally funded program that provides on-reserve home-based health care services to First Nations and Inuit communities in Canada. The Home & Community Care program is not intended to replace services already available through community or provincial health care services, but rather to supplement and link with those services. Care Partners/First Nations Nursing, (CP/FNN) is contracted by the Brant Community Care Access Centre (CCAC) to provide in-home nursing care to Six Nations residents.

Community Engagement

This research project developed as a result of discussions with Six Nations community care providers over several months in 2008. They identified a need to examine the system of palliative care service delivery at Six Nations and expressed an interest and willingness to participate in such an investigation. A participatory approach was used because this research project took place within the context of an Aboriginal health research environment that has established this as one of the key standards for Aboriginal health research in Canada. For more than a decade, the expectation of Aboriginal communities for research within their communities is that it be an ethical process. This includes community consultation on research priorities, decision making, and participation throughout the entire research process. The Canadian Institutes of Health Research published guidelines in 2007 on Health Research Involving Aboriginal Peoples, and the Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans (2010) incorporates a chapter on research involving Aboriginal Peoples. The development of both documents involved a consultation process with Aboriginal peoples across Canada.

Researcher Profile

In qualitative circles, it is considered a serious omission to not provide pertinent information on the researcher or research team members. I am an Aboriginal (Mushkegowuk Cree) researcher who is not from the community, geographic region or tribe of the research setting, but who is nonetheless familiar with the community. In part,

this is through my employment by an organization located at Six Nations that supports Aboriginal health research in Canada. I am, therefore, well aware of the need to be respectful and inclusive of community partners yet not burden them unnecessarily with research-related requests or activities. I have a background in Aboriginal health administration with interests in various aspects of Aboriginal health research including diabetes, breast cancer, and evaluation of health programs. My experience in Aboriginal palliative care was limited prior to commencing work on this project. However, I have long recognized the importance of the topic and was pleased to have the opportunity to work with the community to examine the system of palliative care at Six Nations.

Research Capacity Development

Another important goal of this project was to help develop research capacity within the community of study. The Manager, and to a lesser extent the staff of the Six Nations Home and Community Care Program, were involved in all aspects of the research process of this study. Shared decision-making was an important part of that involvement.

Jurisdiction Issues

Jurisdictional debates over the delivery of health care services to First Nations in Canada began with the Constitution Act, 1867, which defined health care as a provincial jurisdiction and Indian Affairs a federal jurisdiction (Lavoie, Forget and Browne, 2010). An example of these jurisdictional debates is seen in the case of "Jordan's Principle". MacDonald (2012) outlines this principle: a principle that was unanimously approved by

Canada's parliament in December 2007 and aimed to ensure that no status Indian or Inuit child should be denied services due to jurisdictional funding disputes between provincial/territorial and federal governments. The principle was established after Jordan River Anderson died in hospital two years after doctors said he could go home, but would need home care services. However, he did not go home as the province and federal government could not agree on who would pay for his home care costs. (jordansprinciple.ca) MacDonald reports that despite the 2007 member's bill, neither the Government of Canada nor any of the provinces and territories has strong implementation plans.

These debates are reflected in the system of palliative care in place at Six Nations, with the community care providers challenged by not having a mandate to provide acute care nursing services, while observing immediate needs for palliative clients receiving care at home. (Aboriginal Hospice Palliative Care Services Committee Meeting, February 2008)

Kelly, (2011) suggests that the high rates of morbidity and mortality among Aboriginal peoples can in part, be attributed to an uncoordinated, fragmented system of health care service delivery. Another author, Adelson (2005) believes that:

> "The ills and illnesses that have been reported here must be seen, at least in part, as the direct and indirect present-day symptoms of a history of loss of lands and autonomy and the results of the political, cultural, economic and social disenfranchisement that ensued." (p. S59)

She suggests that the path to reducing health disparities between Aboriginal and non-Aboriginal Canadians is linked to a larger political will and policy framework that acknowledges the relationship between inequality and ill-health and that any approach taken to address the problem must consider Aboriginal communities as "active" participants working in response to their colonial situation, rather than passive victims. (S59)

Rationale for Study

An Aboriginal subcommittee of the Hamilton Niagara Haldimand Brant (HNHB) Hospice Palliative Care network (HPCN) was formed in early 2008 to examine and address some of the challenges that were being discussed at HPCN meetings. My supervisor, Kevin Brazil, who was a member of the HPCN, joined the subcommittee and invited me to attend a meeting. From these meetings, a research partnership developed.

The research project's overall aim was to determine how palliative care services provided to the members of Six Nations could be improved in ways that meet the community's values and needs. Palliative care services are currently being provided by a number of agencies and organizations including the Six Nations Home & Community Care program; Care/Partners/First Nations Nursing; and the Brantford CCAC. However, there is nothing in place to integrate care from these various providers.

The Six Nations Home & Community Care program staff emphasized their desire to provide client-centred care, and having previously heard the term "person-centred" care, I chose to use this term when examining this system of palliative care.

Prior to the examination of the system of care, I made a decision early on - with the Manager of the Long Term Care/Home & Community Care Program - that it would be useful to gain input from community members on what the priorities in palliative care were, from their perspective. Thus, a two phase research project was developed, with palliative care priorities from a community perspective being investigated prior to an examination of the system of palliative care at Six Nations.

Research Questions

The research questions that evolved to address the issues discussed above are:

How do various community members of the Six Nations of the Grand River view the current system of palliative care offered to them with regards to its ability to provide person-centred care for its community members?

What do community members/care providers recommend be done to improve the palliative care services provided to Six Nations community members?

There are three identified objectives for this study to be met in order to answer the questions; namely, to:

1. assess how various stakeholder groups within the Six Nations community define person-centred palliative care,
2. determine the degree to which services currently offered on the Six Nations reserve promotes person-centred palliative care, and
3. obtain recommendations from Elders (respected persons recognized within the community as cultural knowledge keepers), family caregivers and care providers

on how to improve palliative care services currently being offered to the Six Nations community.

To answer these questions and meet the research objectives, a qualitative case study design was used. Data were gathered through interviews with Elders and family caregivers in Phase I of the project, and through focus groups with staff from local palliative care service provider organizations in Phase II.

Outline of the Thesis

This thesis includes a review of literature related to Aboriginal palliative care in Canada, New Zealand, Australia and the U.S, within an emphasis on Canadian experiences, and chapters on methods, findings, and a discussion of the findings, the strengths and limitations of the study, and future considerations for research.

Chapter Two: Literature Review

The literature on Aboriginal palliative care is not extensive, but is growing. In fact, as awareness of the significant Aboriginal palliative care challenges has increased over the last few decades, the amount of research being conducted about Aboriginal palliative care has increased. This is reflected in the dedication of an entire issue of the Journal of Palliative Care in 2010 to Aboriginal palliative care research.

The literature search strategy used for this thesis included the search terms "Aboriginal" or "First Nation" and "palliative care" in several library databases (CINAHL, Ovid Healthstar and Medline). The search was not limited by year, but was limited to English language publications.

People living in rural and remote First Nations communities in Canada, to an even greater extent than those living closer to urban centres, are adversely affected by the inadequate availability of primary health care services in general, and palliative care services in particular. This, in great part, is due to significant challenges resulting from their geographic location. This includes the shortage of health professionals in northern communities, the lack of appropriate equipment and facilities and simply the great distances that residents must travel to access appropriate health care. (Kelley, 2010) As such, much of the literature on Aboriginal-specific palliative care services is limited to an examination of those issues.

To date, no research has been conducted on palliative care issues facing the community of Six Nations. However, there is some information on Aboriginal palliative

care in Canada, the United States, New Zealand, and Australia (reviewed below) with an emphasis on the Canadian context.

Kelly & Minty (2007) conducted a literature review of end-of-life issues for Aboriginal patients" that gave a detailed report on articles and reports published from 1988 to 2006. They found 39 articles focused on death and dying or relevant cross-cultural medical caregiving. They concluded from their review that cultural differences exist between medical caregivers and aboriginal patients. These include assumptions and expectations about how communication should occur, who should be involved, and the pace of decision making regarding care. Aboriginal patients, for example, may value indirect communication, use of silence, and sharing information and decision making with family and community members. In contrast, medical practitioners often use rapid and direct communication and may or may not value sharing information with family members of a dying patient.

Framework for Conducting Palliative Care Research in First Nations Communities

Prince & Kelley (2010) presented a framework for conducting palliative care research with First Nations communities, based on a conceptual model developed by Kelley (2007). As they describe, the model: "depicts a bottom-up community development process to build a palliative care program in four phases: having antecedent community conditions for change, experiencing a local catalyst for change, creating a local palliative care team, and growing the palliative care program." (p. 48)

The framework was developed after five years of work with 12 First Nation communities in the Treaty 3 area of northwestern Ontario, one of the larger treaty areas in

the province of Ontario. Ojibway, or Anishinaabe people are the primary residents of the Treaty 3 communities. The framework consists of five components: Community capacity development, cultural competence and safety, participatory action research, ethics and partnerships.

The authors reported that after the five years and application of the five components, partnerships have persisted, and the First Nations remain committed to the process because they have achieved real benefits in developing their capacity to provide palliative care. Benefits include the development of palliative care resource materials (manuals, curricula, pamphlets) developed with the input of community members, and increased capacity to provide palliative care services within the community with the development of local palliative care teams in 3 of the communities.

Northwestern Ontario "remote" experiences

Kelly et al. (2009) discussed three themes in their study of bereaved Aboriginal family members who had a family member die at the Meno Ya Win health centre in Sioux Lookout of northwestern Ontario: communication, caregiving, and environment, with respect as an underlying principle. The bereaved family members discussed the communications they had with the care providers involved in the care of their family member who was dying. They preferred direct communication, without being given any false hope. With respect to caregiving, participants were generally satisfied with symptom control, although one participant reported that a nurse told them to be quiet while they were singing after their loved one had passed. Appropriate facilities was an

important part of the environment for the participants; namely, appropriate space for the many family members and friends that want to be close when a loved one is dying.

St. Pierre-Hanson and colleauges, (2009) outlined a culturally safe program of palliative care delivery at the Sioux Lookout Meno Ya Win health centre. They define cross-cultural patient safety as "the safe and successful delivery of health care services across the barriers to the understanding and identification of client needs." (p. 43) They reported that on average, there are 30 deaths a year at the hospital. Elder consultations revealed five main areas where development was needed: access to interpreters; Aboriginal care providers (so encouraging Aboriginal youth to enter health professions); traditional foods prepared in a traditional way; funding for Aboriginal medical escorts who have cardiopulmonary resuscitation (CPR) and first aid training; and respect for Aboriginal spiritual healing and healers. The authors also reported that the local hospital has developed an organizational research culture that leads to "forward thinking, practice/policy relevant research and strengthens the collaborative relationship between researchers, decision makers, and care providers". (p. 44)

A new hospital under construction at the time this article was being written incorporates some of the findings from this and other related studies such as providing large rooms to accommodate the many family members that are often present in end-of-life situations for Aboriginal people, a separate ceremonial room, and a special area for preparing traditional foods and medicines.

Aboriginal Palliative Care Research in other parts of Canada

In the British Columbia interior, health care providers reported that palliative care services were most likely to be used by white people and that cultural minorities were more likely to "take care of their own". (Castleden et al., 2010, p. 486) The authors reported that Aboriginal peoples were "invisible" in this particular area of British Columbia, and that if health care providers were aware of their existence, they had many mistaken beliefs and ideas about Aboriginal peoples and their palliative care needs. The authors reported that they had identified four "necessary elements" to enhance palliative care service provision in the region. These elements include:

1. allocate resources to establish strategies such as culturally specific practices (e.g., smudging) that will facilitate experiencing a good death;
2. Provide culturally safe care that supports people in claiming and embracing their Aboriginal identity at end-of-life;
3. Give care in spaces that do not re-institutionalize Aboriginal people; and
4. Offer training to formal and informal service providers regarding cultural practices in death and dying. (p. 488-9)

The authors further suggested that health care providers must more actively consider the existence of an Aboriginal population in the region and that they also have the right to access high-quality health care services; that cultural safety training be made available for health care providers; and that recruitment of Aboriginal palliative care providers take place to address the challenges in access to palliative care services for Aboriginal people.

Hampton and colleagues, (2010) reported that a community action research method was used to inform health care providers about the needs of Aboriginal people receiving care in facilities at end of life. Elders in Saskatchewan were interviewed and the researchers identified the following themes from the interviews: Completing the Circle; Gathering of Community: Preparing for Death; Care and Comfort; Moments after Death; Grief, Wake, and Funeral. The authors suggested that different understandings of care exist between western bio-medical-oriented models of care and Aboriginal cultures, and that this is a major barrier to appropriate end of life care for First Nation or Aboriginal People. Furthermore, they noted that restructuring policies governing hospital and local service delivery systems is required in order to provide culturally appropriate care.

Hotson and colleagues (2004) conducted interviews with key informants (Aboriginal residents living in remote communities, community Elders, and health care providers) to identify and describe palliative care services available to residents of remote Aboriginal communities in northern Manitoba, as well as local attitudes about death, dying and palliative care. They also explored obstacles related to the delivery of palliative care services. The authors reported that many Aboriginal patients are transported to large urban centres to die away from family and friends although their preference would be to die at home. The authors suggested that in consideration of the geographic isolation that many Aboriginal people face in Canada, the following is required to provide effective palliative care:

1. Patient-specific care plans be created for use in the remote community;

2. Effective lines of communication are established between remote health care providers and urban specialists;
3. Health care providers and family care-givers be properly trained to fill their respective roles; and
4. Appropriate guidelines and resources be available in the community to support this type of care. (p. 25)

The authors concluded that providing the appropriate equipment, supports and education can be an effective way to provide palliative care services within the community.

Palliative Care for Aboriginal People in Australia, New Zealand and the U.S.

McGrath (2010) presented a "living model" of Aboriginal palliative care service delivery with international implications – "a generic model incorporating all important factors that can be applied to the unique circumstances of each health care service working with Aboriginal people during the end of life trajectory". (p. 59) Although the research was based on palliative care service delivery for Aboriginal Australians, the author suggested the model is relevant to Canadian Aboriginal palliative care service delivery as well. The model incorporates the following seven principles articulated by Aboriginal participants and affirmed by Aboriginal health experts in Australia: equity; autonomy/empowerment; trust; humane, non-judgmental care; seamless care; emphasis on living; and cultural respect. Many of the issues faced in the Canadian context are similar to those experienced in Australia. Currently, relocation is often necessary for

terminally ill patients even though there is a strong preference to receive care from Aboriginal providers in one's home (in order to perform culturally relevant ceremonies before, during, and after death)

Muircroft and colleagues (2010) reported that Maori people of New Zealand suffer from poorer health than their non-Maori counterparts, including higher cancer incidence and mortality rates, and lower life expectancy. As might be expected, their palliative care needs are significant. A national Palliative Care Strategy implemented in 2001 recognized the distinct palliative care needs of the Maori, but the authors suggested that active consultation and direct involvement of Maori people and health providers are required in order to identify Aboriginal palliative care needs and plan appropriate services.

Aranella and colleagues (2010) described an interdisciplinary palliative care "train the trainer" training program in the U.S. developed by the Indian Health Service (IHS) and the National Cancer Institute for health professionals in the IHS that took place in 2006. The program was developed following a 2004 needs assessment that revealed an urgent need for palliative care services including pain management, advance care planning, hospice care and bereavement support. The authors suggested that the program, which comprised a multimedia program of self-study along with 3 seminars that followed a culturally-adapted curriculum entitled "Education in Palliative end-of-Life Care for Oncology (EPEC-O), increased clinician self-reported knowledge and confidence to train others in palliative care service provision. "It also stimulated the incorporation of palliative principles into practice as well as the development of previously unavailable

palliative services at the Indian health system practice sites of seminar participants." (p. 20) The authors reported that of the 67 participants, nearly half had conducted or definitively planned palliative care education sessions and 57 percent started new palliative services at their practice sites. They also reported, however, that knowledge retention in this group deteriorated over time, indicating the need to reinforce principles of palliative care.

DeCourtney, Branch and Morgan (2010) report similar issues regarding end-of life needs for Alaskan and Canadian Aboriginal peoples. Both groups often live in isolated communities. Dying people are often transported away from family and friends and often die alone in hospital, hundreds of miles from their home communities. This study examined traditional ways of caring for the dying that are based on a sound knowledge of cultural values and preferences around death, as well as caregiver needs, and how a palliative care program could assist in caring for people in their own communities. They reported that Alaska Native people would prefer to care for their dying at home but that they needed support for this. They suggest that considering the geographic location, harsh climate, mainstream palliative and hospice care will never be available to most of Alaska's Aboriginal peoples, but that by "combining traditional and family caregiving practices with modern medicine and telecommunications, it may be possible to establish effective palliative care programs." (p. 29)

Medicine Wheel Teachings and Palliative Care

Clarke and Holtslander (2010) applied medicine wheel teachings to the care of a person at end of life. Using principles associated with the four directions of the medicine wheel (i.e., the physical dimension in the east, the emotional dimension in the south, the mental dimension in the west, and the spiritual dimension in the north), they suggested that care providers should be aware of each of these dimensions and how they may affect client needs at different stages of their illness. They also reported that health care providers should not assume that all Aboriginal people follow "traditional" ways, and that there are various ways to live a traditional life.

Appropriate Community Engagement Strategies in Palliative Care Research

Hanson (2010) outlined a process of developing relationships with Aboriginal Elders and Cultural Advisers to develop culturally appropriate palliative care. Elements of the seven-step iterative process included: readiness, requirements, requests, respect, response, results and rounding. The process described is culturally sensitive and respectful, and one that engages people in a way that ensures they know that their contributions are valued, and that the outcomes will be shared with them.

National Initiatives Addressing Aboriginal Palliative Care Issues in Canada

Hanson and associates (2007) prepared a report for the Canadian Hospice Palliative Care Association on the current state of Aboriginal Hospice Palliative Care (AHPC) in Canada within the context of national developments in the field. The authors

noted that Health Canada provided funding for this initiative, which included surveys and interviews to collect data and a two-day national meeting, but that it was neither a formal consultation nor a comprehensive research project, both of which the authors report are needed. The report outlined several aspects of Aboriginal palliative care issues, including jurisdiction and policy issues, education and training needs, cultural competence, health care service delivery, funding, Aboriginal-specific palliative care guidelines and protocols, grief and bereavement support and services gap.

Recommendations that arose from the process were: 1) Recognize and nurture AHPC activities underway in communities; 2) Public education and awareness building; 3) Document and share leading practices in AHPC; 4) Support local capacity building; 5) Collaborative Training and Education; 6) Develop and support joint working group; 7) HPC Integration with delivery of other health care services; 8) Roster of Programs and Services; 9) Addressing Access Issues; 10) Use of common and accessible language; 11) Investment in Cultural Competence at all Levels; and 12) National Leadership and Funding.

The National Aboriginal Health Organization prepared a discussion paper on end of life/palliative care for Aboriginal peoples in 2002. Recommendations included:

1. Ensure active and appropriate participation of relevant Aboriginal organizations in the development of the National Action Plan on End of Life care.

2. Conduct necessary research to define responsible, competent, compassionate, appropriate culturally relevant and ethically sound end-of-life palliative care for First Nations, Inuit and Metis people.
3. Build on the needs assessments completed under the umbrella of the Home and Community Care Program to ensure the end of life needs are well defined for First Nations, Inuit and Metis populations; and to further include an assessment of the needs of urban Aboriginal people.
4. Develop and implement a strategy to ensure the education and training of the appropriate number of Aboriginal health workers in all fields necessary to provide culturally relevant and sensitive care to Aboriginal Peoples in all health care settings.
5. Develop strategies for appropriate provision, professional development and other supports to health care workers employed in Aboriginal communities to ensure an ongoing high standard of palliative care.
6. Create a coordinating mechanism with full involvement from federal, provincial, territorial and Aboriginal governments and organizations to identify and resolve jurisdictional issues arising between governments, to achieve a coordinated approach to palliative care.

Summary

The literature demonstrates that there is still a lot of work to be done provincially, nationally and internationally to improve the delivery of palliative care to indigenous

populations. The studies examining the delivery of palliative care in remote and rural Aboriginal communities in Canada, the U.S., New Zealand and Australia all reported that Aboriginal people prefer to die at home, that resources are not always available for that to happen, and that there is a need for culturally appropriate palliative care services to be developed for use both on and off-reserve.

Chapter 3: Methods

Research Approach

An interpretive intrinsic qualitative case study approach was utilized in this research project. Stake (1995) describes an intrinsic case study as one in which:

> "The case is given. We are interested in it, not because by studying it we learn about other cases or about some general problem, but because we need to learn about that particular case. We have an intrinsic interest in the case, and we may call our work intrinsic case study." (pg. 3)

He also explains: "Case study is the study of the particularity and complexity of a single case, coming to understand its activity within important circumstances." (p. xi)

At the outset of this research project, Stake's definition of an intrinsic case study seemed most appropriate for this study. As Stake writes:

> "Let us use the Greek symbol Θ (theta) to represent the case, thinking all the while that Θ has a boundary and working parts. In our work in social sciences and human services, Θ is likely to be purposive, even having a "self". The case is an integrated system. The parts do not have to be working well, the purpose may be irrational, but it is a system. Thus, people and programs clearly are prospective cases." (p. 2)

Given that the purpose of this study was to examine the system of palliative care service delivery at Six Nations of the Grand River, with an interest in learning about the

particular elements of the systems and how they work together with an emphasis on learning ways to improve the system, Stake's case study seemed quite appropriate. The case here is one system of care, thus, it may be called a single case study.

Stake uses the term "issue questions" as his primary research questions: "- in order to force attention to complexity and contextuality. I also use them because identification of issues draws attention to problems and concerns." (p. 16)

He also writes: "Issues are not simple and clean, but intricately wired to political, social, historical, and especially personal contexts. All these meanings are important in studying cases". (p. 17)

These ideas fit well with the current project because the research questions for this project were designed to examine the issues surrounding the delivery of palliative care services within the context of the unique, complex system of care that exists at Six Nations. In other words, the case cannot be separated from its context.

Interpretive Inquiry. Stake advances the idea that "all research depends on interpretation" (p. 43) and that the researcher ultimately comes to offer a personal view, and that "an ongoing interpretive role of the researcher is prominent in qualitative case study." (p. 43) Given this, the first-person singular has been used in the writing of this thesis to recognize the interpretive nature of this qualitative case study.

Data Sources

Interviews with community Elders and family caregivers of Six Nations members receiving palliative care services and focus group discussions with Six Nations health

care providers were the main sources of data. As expected in case studies, multiple types of data were sought. Additional data sources included notes from my participation in Hospice Palliative Care Network - Aboriginal Services subcommittee meetings and correspondence with community partners.

Methods and Underlying Principles

An important factor in the development of this project was the underlying approach that influenced the way that this research study was carried out. It may be described as an "Indigenous methodology", although no single Indigenous method exists. Rather, principles that are commonly highlighted in ethical and effective research that takes place within Aboriginal communities were utilized.

Jacklin and Kinoshameg (2008) published an article entitled "Developing a Participatory Aboriginal Health Research Project: Only If It's Going to Mean Something". They report that the subtitle of the article was a response given by an Aboriginal youth when asked if she would be willing to complete a questionnaire. This idea, "only if it's going to mean something", played a role in the development of this project. In fact, the principles outlined in this article served as the guiding principles used in the development and implementation of this research project.

In the article, Jacklin and Kinoshameg outline eight principles of appropriate community-based participatory research. They include:

- Partnership – Local involvement and participation in planning and implementation

- Empowerment – research as a process that enhances community empowerment and moves towards self-determination
- Community Control – community maintains ownerships and control of research process and outcomes
- Mutual Benefit – working in partnership with and for the community for a mutually beneficial outcome
- Holism – use and production of unified or holistic knowledge
- Action – knowledge produced is used for action
- Communication – commitment to communication, dissemination and knowledge translation of research and results
- Respect – respect for local research philosophy and culture

Another related principle employed in this research project was that of reciprocity. Chapter 9 of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, December 2010 (TCPS2) published by the Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada "Research Involving the First Nations, Inuit, and Métis Peoples of Canada" discusses reciprocity in its preamble. The document notes that historically only researchers gain benefits from conducting research (p. 105). One aim of this research has been to ensure that the community of Six Nations

directly benefits from this research taking place; namely, access to an improved system of palliative care delivery to its residents.

Community engagement has already been identified as an important aspect of this research project, and is also discussed extensively in Chapter 9 of the TCPS2. Article 9. 1 states: "Where the research is likely to affect the welfare of an Aboriginal community, or communities, to which prospective participants belong, researchers shall seek engagement with the relevant community." (p. 110)

Article 9.2 states: "The nature and extent of community engagement in a project shall be determined jointly by the researcher and the relevant community, and shall be appropriate to community characteristics and the nature of the research." (p. 111)

This project developed with a relationship-building process that began at a meeting of the Aboriginal services subcommittee of the Hospice Palliative Care Network in early 2008. Throughout the entire research project (2008 to 2011), I attended these meetings, which took place every one or two months. I also met and corresponded with the Manager of the Six Nations LTC/HCC. The Manager was actively engaged in the Hospice Palliative Care Network and expressed a desire to more formally develop a community-based palliative care team that had been proposed locally at the Six Nations LTC/HCC program, but had not yet taken shape. She also discussed some of the challenges in accessing palliative care services for Six Nations residents, and through these discussions, we developed a research partnership.

An important aspect of the community engagement process used in this project was ongoing communication with the Six Nations Home & Community Care Manager, as

well as other staff members within that organization. Their involvement was sought at each stage of the research process, including the development of the research question, vetting of the interview questions for the Elders and family caregivers, and review of summary reports at different stages of the research process. Through this process, we agreed that the interviews with Elders and family caregivers would aim to gain an understanding of the palliative care experiences they were familiar with, their perceived priorities in care, and what they thought would be an ideal palliative care experience.

Trustworthiness. The engagement activities at the different stages of the research process were also an important way to ensure the credibility, dependability and confirmability of the findings reported in this thesis.

Lincoln and Guba (1985) developed trustworthiness criteria to be used in assessing qualitative research. They describe credibility as the extent to which findings and interpretations are credible. It can also be considered as the "confidence in the truth of the findings." (http://www.qualres.org/HomeLinc-3684.html) Dependability can be described as "showing that the findings are consistent and could be repeated." (http://www.qualres.org/HomeLinc-3684.html) Confirmability has been described as "a degree of neutrality or the extent to which the findings of a study are shaped by the respondents and not researcher bias, motivation, or interest." (http://www.qualres.org/HomeLinc-3684.html)

The strategies employed to ensure the credibility, dependability, and confirmability of the findings in this study included, as stated above, the iterative engagement with community partners at several stages of the research process to reduce

researcher bias, prolonged engagement with community health care providers via meetings and correspondence over a three-year period, investigator triangulation – a review of the raw data and the process used in arriving at themes by another investigator. Denzin (as cited in Stake (1995)), describes investigator triangulation as having other researchers take a look at the same scene or phenomenon… (p. 113) [to gain the needed confirmation, to increase credence in the interpretation] (p. 112)

Member checking was also a strategy used. Stake (1995) describes "member checking" in this way:

"In a process called "member checking" the actor is requested to examine rough drafts of writing where the actions or words of the actor are featured, sometimes when first written up but usually when no further data will be collected from him or her. The actor is asked to review the material for accuracy and palatability. The actor may be encouraged to provide alternative language or interpretation but is not promised that that version will appear in the final report. Regularly, some of that feedback is worthy of inclusion." (p. 115)

Recruitment and Sample

Recruitment commenced in February 2009 once ethical approval had been granted by the Six Nations Ethics Committee (October 2008, revision January 2009), the Hamilton Health Sciences/McMaster University Faculty of Health Sciences Research Ethics Board (January 2009), and the Hamilton Niagara Haldimand Brant Community

Care Access Centre ethics review process (December 2008). (see Appendix A for ethics approval letters)

The sampling strategy used to recruit the research participants can be described as purposeful and criterion sampling, as described by well-known qualitative researchers Miles and Huberman (1994) and Creswell (1998). Purposeful sampling in qualitative research is the purposeful selection of participants that are likely to be a rich source of information that are tied to the purpose of the research (Patton, 1990). One such type of sampling is based on ensuring that all data sources meet a specific criterion or set of criteria. In this study, Elders were recruited for one-on-one interviews because they are information-rich data sources (the knowledge holders in the community). Family caregivers of Six Nations residents who received palliative care at home were recruited if they had experience with the care delivery system at Six Nations and could share their views on the system. Focus group participants were invited because they were members of organizations providing palliative care services to Six Nations residents and therefore knowledgeable about service-provision issues. Specifically, the criteria used to select focus group members were: being employed by an organization that provides palliative care services to Six Nations members, and who are involved in the provision of that care. I contacted a manager in each of the three organizations providing palliative care service delivery at Six Nations and extended an invitation to staff members meeting eligibility criteria to participate in a focus group discussion on palliative care delivery at Six Nations.

Thus, the selection criteria were as follows:

- "Caregiver" participants: Any Six Nations member who has been involved in the day-to-day care of an individual who received palliative care in the Six Nations community at least one year after and before two years had passed since providing care (to ensure adequate recall of events and perceptions); was willing to share their experiences with palliative care service providers; speaks and understands English; and who was willing to give informed consent to participate in the study.
- "Elder" participants: Any Six Nations member recognized as an Elder by the community (who therefore has knowledge about the community and culture); was willing to share thoughts and experiences about the care of the seriously ill from a cultural perspective, without regard to a specific time period; speaks and understands English; and who was willing to provide informed consent.
- "Focus Group" participants: Individuals who were employed by an organization providing palliative care to Six Nations members (i.e., Six Nations Long Term Care/Home & Community Care Program (LTC/HCC), Care Partners/First Nations Nursing (CP/FNN), or Brant Community Care Access Centre (Brant CCAC)) who directly or indirectly, provided palliative care services to Six Nations members; speaks and understands English; and who was willing to give informed consent to participate in the study.

The family caregivers and Elders were contacted by Six Nations Home & Community Care Program staff members who described the study and extended an invitation to participate in the research. I decided on this recruitment strategy because

members of that organization could identify community Elders and family caregivers for their palliative care clients receiving care at home. (see Appendix B for recruitment letter).

Data Collection Instruments and Processes

Designing the Interview Guides. I designed the interview questions used in this study using the same process as when I developed the research question. First I developed a set of questions (which was approved by my supervisor). The Six Nations LTC/HCC Manager then reviewed the questions to ensure that they reflected the discussions and goals of the project. I then drafted the interview guides and brought them to a meeting with the LTC/HCC manager and a team of case managers who work with community members in need of palliative care in their homes. (Because they work to meet the day-to-day care palliative care needs of the community, the Six Nations LTC/HCC Manager felt they would be excellent judges of what would be appropriate to ask Elders and family caregivers.) This session was an opportunity for the staff to give feedback on the questions.

The first part of the interview included questions specific to a palliative care event. These questions were initially designed for use with only the family caregiver interviewees, but it was decided that the same interview guide would be used for the Elder interviewees because they may be aware of a situation in which a person received care at home prior to dying, as was frequently the case for many of the Elders. (See

Appendix C for interview guide) This would also allow me to compare responses to the same questions across these two disparate groups.

I developed the interview guide for the focus groups with the aim of understanding the strengths and weaknesses, successes and challenges in providing palliative care at Six Nations from the perspective of the care providers. (See Appendix D for focus group interview guide) Because there are different levels of care that may influence service delivery, focus group participants were asked to comment about providing palliative care at the different levels (i.e., system-level strengths and challenges, program-level strengths and challenges, and individual-level strengths and challenges). The system level includes all three of the organizations providing services to clients, whereas the program level included only the organization for whom focus group members work, and the individual level inquired about the personal challenges they faced in carrying out their role. A handout was provided to all focus group participants at the start of each focus group outlining these levels of care. (See Appendix E for focus group handout)

I contacted prospective Elder and family caregiver study participants by telephone once I had received their contact information, and then established a place, date and time for each individual interview. 13 of 15 interviews took place in the home of the interviewee and the other 2 took place in the interviewee's work location. All interviews took place between February and October 2009.

I presented full details about the study when I met each study participant, who also received a copy of the consent form/information sheet. To ensure I received fully

informed consent from each participant, I read the information and consent forms out loud to each interviewee. (See Appendix F for consent form) I also informed them that they were receiving a $40 Walmart gift card for participating in the interview. After answering any questions presented by a participant and she or he had signed two copies of the informed consent form, I countersigned the forms, retaining one for my records and giving the other to the participant. Then I began the interview. With prior permission, all interviews were tape recorded for accuracy.

I invited focus group participants to participate by telephone. The participating organizations included the Six Nations Long Term Care/Home & Community Care Program (LTC/HCC), Care Partners/First Nations Nursing (CP/FNN), and the Brant Community Care Access Centre (CCAC). Focus groups took place between April and September 2010. Four focus groups took place – two with the Six Nations LTC/HCC staff and one each with the Brant CCAC case managers and with the First Nations Nursing/Care Partners nursing staff. The second focus group with the Six Nations LTC/HCC staff took place because key personnel were unable to attend the first focus group as a result of a death in the community, and the Manager of the Six Nations LTC/HCC felt it was important to have their perspectives.

I followed the same process with palliative care providers who participated in a focus group. I presented full details about the study and reviewed the consent form/information sheet with the participants. Once all participants had signed both copies of the informed consent forms, I countersigned them and retained one copy for my records. I then began the focus group discussion, audio taping the proceedings with prior

permission of group members. I also provided each focus group participant with a $40 Walmart gift card.

Analysis of Elder and Family Caregiver Interviews

With respect to the analysis stage of the research, I considered the involvement of the participants to be an essential piece of a respectful and participatory process. Once I transcribed each interview, a second visit was arranged with each participant to review the verbatim written document produced from the audiotape of an interview (transcript). The purpose for the second visit was a member checking session to ensure that the participant's views were well presented, but it was also an opportunity for the participant to take part in the analysis.

Another concept I used when analyzing transcripts of individual and group interviews was proposed by Linda Tuhiwai Smith (1999) in "Decolonizing Methodologies, Research and Indigenous Peoples". She writes at length about the importance of sharing knowledge:

"I use the term 'sharing knowledge' deliberately, rather than the term 'sharing information' because to me the responsibility of researchers and academics is not simply to share surface information (pamphlet knowledge) but to share the theories and analyses which inform the way knowledge and information are constructed and presented. By taking this approach seriously, it is possible to introduce communities and people who may have had little formal schooling to a wider world, a world which includes people who think just like them, who share in their struggles and dreams and who voice their concerns in similar sorts of ways. To assume in advance that people will not be interested

in, or will not understand, the deeper issues is arrogant. The challenge always is to demystify, to decolonize." (p. 16)

This idea of "demystifying" research and its results reflects my intent to make knowledge gained during this study accessible to the Elders and family caregivers who participated, to the community of Six Nations as a whole, to the community health care providers, and to the academic community interested in palliative care services, and Aboriginal health care services in general. I have made an effort to explain the results in a way that will make sense to all audiences. One way was to avoid using a lot of jargon or unfamiliar language.

Analysis Framework. The framework used for the analysis of the interview data for this research is found in "Doing Qualitative Research", Crabtree & Miller (1999). An overall interpretive process that is used in qualitative research is described and outlines a number of organizing methods that may be used. An "editing" organizing style was employed in the analysis of the interview data in that the data is entered and a classification or coding scheme follows.

Interpretive Process. The five phases of the interpretive process include: Initial descriptive phase of interpretation; Organizing; Connecting; Corroborating/ Legitimating; and Representing the account.

Describing. The describing phase includes preliminary steps to the analysis that situates the researcher within the interpretive process. The researcher examines his/her own beliefs and values, the paradigm in which the research takes place, and how these influence the research. Elements of this phase are described in the Introduction chapter of

this thesis under: Six Nations of the Grand River - Community Description and Researcher Profile.

Organizing. As per the "editing" analysis style described by Crabtree & Miller, the organizing phase includes: entering the text and later developing a classification or coding scheme; identifying categories through direct interaction with text; entering the text and segmenting data by identifying the information that is most pertinent to the research question and then categorizing, cutting, pasting, splitting and splicing.

Connecting. The connecting phase specifically refers to the discovery of themes & patterns, to making linkages between categories, to developing models.

Corroborating/Legitimating. Crabtree and Miller describe this phase as a process "to make more certain and to confirm" and includes: re-viewing the texts after initial or later analysis seeking to corroborate the multiple "truths" or perspectives voiced in the texts and by the analysts to confirm internal consistency of interpretation; searching for alternative explanations, disconfirming evidence, negative cases, and member checking. These three phases are discussed more thoroughly in this chapter.

Representing the account. The final stage of the interpretive process is the sharing of new understandings and interpretations, and finding some way to represent an account of what has been learned in the researching. Chapter Four of this thesis includes the findings from this research project and Chapter Five is a discussion of the findings and together, they represent this final phase of the interpretive process.

Initial approach to analysis of interview data. I used a two-prong approach to analyze the interview data. First, I compiled "Important Aspects of Care" lists with

participants, and secondly, I assembled participant responses to individual questions in the interview guides in a table to organize the data by specific interview questions. These steps reflect the "organizing" phase of the interpretive process and an attempt to analyze the data from two angles, to gain a higher degree of confidence in the findings.

To create the "Important Aspects of Care" lists, I highlighted relevant phrases that stood out as meaningful to this topic in the initial review of the interview transcripts. I then presented the lists to participants in the second interview, along with the interview transcripts, to provide an opportunity to clarify anything they had said earlier. They also had the opportunity to add items to the "Important Aspects of care" lists. I read aloud each highlighted statement from a transcript to the participant in that interview and then asked for a response. For instance, "Last time we met, I asked you "X" question, and you responded with "Y". I took this to indicate that you feel that "Z" is an important aspect of care. Would you agree with that or change it in any way?" Thus, the participants contributed directly to the analysis of initial findings by confirming the importance of various aspects of care they had identified in their first interview.

Once themes emerged in the analysis of data by the responses to questions, I arranged the items in the "important aspects of care" list to determine whether they would fall under the themes that already existed or if I needed to add new themes to the list. These steps represent the "Connecting" phase of Crabtree & Miller's interpretive process.

The Corroborating/Legitimating phase followed the "connecting" phase and commenced with the review of the transcripts and "Important aspects of care" lists with participants. This phase continued throughout the entire process of analyzing the

interview data, with a re-viewing of the tables and interview transcripts at each stage of the analysis. Thus, there are two types of corroboration happening. The first, with participants, confirms that my initial interpretations were consistent with the participant's sentiments, and throughout the secondary analysis of the group data, I returned to the data to confirm that identified themes were true to the data. A second opportunity for corroboration with participants took place with a summary report of the themes identified in the interview data being returned to them for comment.

Once all the follow-up interviews were completed, I developed tables to organize responses by individual interview question. I highlighted significant statements and noted common responses as themes. I did this for all of the questions.

These tables and a document outlining the themes were reviewed by my supervisor for investigator triangulation purposes. Upon his review, he confirmed his agreement with the themes identified.

The first step in the analysis of the "Important Aspects of Care" lists was to group items into categories. The easiest way to do this was to print the lists off and cut the pages into strips with each item on one strip. The strips of paper were then grouped into themes.

Focus Group Data Analysis

I recorded and transcribed each focus group and sent a summary report of each focus group to each organization to provide a record for them of the focus group, and to

provide an opportunity for them to give feedback on the report as a form of member-checking.

As I did when analyzing individual interview data, I used the "editing" approach to analyze the focus group data. The summary reports were read through, with an aim to identify broad themes. Once broad themes were identified, the summary reports were read through again, with paragraphs being coded by theme heading. I then returned to the focus group transcripts to ensure that the theme headings were consistent with the transcript data.

While themes were sought in the analysis of the data, it soon became apparent that there were strengths and challenges that were unique to each organization. Thus, themes were identified, but I also added a new category -- "Within-Program Strengths and Challenges".

I sent a summary report outlining the focus group findings to all organizations for member-checking, with an invitation to review the document and respond with any feedback. No feedback was returned by focus group participants.

Ethical considerations

From the outset of the research project, I was keenly aware of the need for the research to be conducted in a highly ethical manner. Six Nations is one of the few reserves in Canada that has its own ethics review board, and requires researchers to complete a comprehensive application that outlines all aspects of the research project, including a description of: the need for and value of the research; the methods; the

research participants; how data will be stored; who has access to data; and who has ownership of the data once the research is complete. Once the ethics protocol was completed, it was submitted to the Council Secretary of the Six Nations Band Council who then forwarded it to the Six Nations Ethics committee for review. Once approval was granted by the Six Nations ethics board, ethics approval was sought from the Hamilton Health Sciences/McMaster University Faculty of Health Sciences Research Ethics Board with a copy of the Six Nations ethics application and approval letter attached.

Presentation of Findings

In the next chapter, the findings from the study are presented. To easily differentiate a direct quote of a participant from my voice, the quotes have been presented in *italicized text*. Also, abbreviations are used to reference a speaker. For example, (E1) refers to the first Elder I spoke with and (FC6) refers to the sixth family caregiver. Some of the quotes were modified by adding words [in parenthesis] to improve readability without changing meaning, as outlined by Krueger. (1998) (p. 74)

Chapter 4: Findings

Study Participants

Eight Elders and seven family caregivers participated in one-on-one interviews, and twenty-one care providers from three organizations participated in the four focus groups ranging from five to seven members each.

Recruitment of interview participants took a significant amount of time. A contributing factor in delays in recruiting family caregiver participants was the selection criteria requirement that the interview take place at least one year after the death of their loved one. In Haudenosaunee culture, a feast is held for a person one year after their passing, and it was felt that it was appropriate to wait until this grieving period was over before requesting an interview.

Focus group participation rates were excellent. All CCAC case managers who oversee Six Nations clients were present for the CCAC focus group, as were all the Six Nations Home & Community Care case managers, along with social workers and the traditional wellness counsellor in their group. Only one of the eight nurses employed by First Nations Nursing was absent from the First Nations Nursing focus group because of a scheduling conflict.

Phase I of this research project included interviews with Elders and family caregivers of persons who had received palliative care services in their home at Six Nations. The eight Elders and seven family caregivers were identified by Six Nations Home & Community care staff and were interviewed in their homes or work location. The main aim of the interviews was to inform the care providers of the priorities in care,

as identified by the participants. Analysis revealed a number of themes describing priorities in care from the perspectives of the participants. These may be categorized as: 1) personal aspects of caregiving, 2) practical aspects of caregiving, and 3) cultural considerations in providing palliative care to Six Nations members.

Phase II of the project consisted of focus group discussions held with members of the three organizations that provide palliative care services to on-reserve members of Six Nations of the Grand River. The Six Nations LTC/HCC focus groups included nine individuals, including case managers, social workers, and the Six Nations Traditional Wellness Coordinator. The CP/FNN focus group included seven nurses, and the Brant CCAC focus group included four case managers and a senior manager. The focus groups took place within the offices of each of the participating organizations and they were recorded and transcribed. A summary report of each focus group was sent to each organization to provide a record for them of the focus group, and to provide an opportunity for them to give feedback on the report as a form of member-checking.

The aims of the focus groups were to identify the strengths and challenges in the local system of palliative care delivery as a whole, and to identify the strengths and challenges encountered at the program and individual levels, and also to provide recommendations on improving the system of care, based on focus group participants input.

One main theme emerged from the focus group discussions. It revolved around relationships and the rapport between the provider organizations, with a number of related subthemes. Other themes included cultural considerations in care and broader system

factors that influence care. As all of the organizations have unique roles, strengths and challenges, these are discussed in addition to the issues related to relationships and rapport.

Phase I Interviews

The interviews were reviewed twofold. As many of the questions in the interviews asked questions that were of interest to the care providers, the data were first analyzed by question, whilst developing themes across questions resulting in "Important Aspects of Care" as set out by the interview participants.

Elder Interviews

Question one: "What do you remember about the care they [names used] received? What stands out for you?"

The purpose of this question was to identify the most salient features of care, as perceived by the participants. This question was asked of both the Elder group and the family caregiver group, as it was believed that most Elders will have familiarity with a home care/home death experience, though not necessarily direct involvement in providing care themselves. In fact, a number of Elders had been involved providing care to an individual in the home prior to dying.

The Elders outlined several day-to-day care needs, i.e., bathing, medication management, feeding of patients, and housekeeping. They also discussed the personal

aspects of caregiving: "*So she moved in with us, and what we did was, we set it up like it was her own bedroom so that everything around her would be familiar*." (E2)

And: "*She really looked forward to their [home care provider] visit. She got quite attached to some of those gals*." (E4)

In response to another question, one Elder stated: "*Your patient is alive and has feelings, so you have to be very aware of that and have to know that how you treat that patient affects their recovering*" (E8) The sentiment of always remembering that you're dealing with a person with thoughts and feelings emerged quite strongly, as indicated in yet another statement about this: "*They treated her respectfully and they listened to the way she saw things, and did it her way, and that was really important to her*." (E4)

Question two: "What things did the care providers do that mattered the most?"

The Elders had experiences that varied significantly from each other, i.e., one Elder previously cared for his grandmother who lived with him, but she died suddenly while still fairly independent. This Elder currently receives home care services himself, and these care services are what he is familiar with, so this is what he spoke about. This was similar for another Elder who had been injured and received care at home. She also had her ailing grandmother live with her family as she was growing up. She tells of being grandma's nurse when she came home from school. In any event, the Elders spoke of their personal individual experiences that reflected the needs they themselves experienced, i.e., "*They cleaned the wound and dressed it*." (E8)

The various services specifically mentioned were: physiotherapist home care, bathing, housekeeping, treating the dying person respectfully and providing care the way

that the patient wanted, pain management, provided comfort to family, communicating with family about the patient's condition, and receiving services from Meals on Wheels.

The idea that emerges is that the care providers meet the individual care needs, whatever they are. This thought came up when responding to other questions as well. One Elder stated: "*They were most helpful for whatever she needed, we got service right away.*" (E4), and another said: "*They were very, very helpful, they did all that was necessary. That was my experience*". (E8)

Clearly there was an expressed need to develop and follow personalized care plans for the dying.

Question three: "What was least helpful?"

All of the Elders were generally happy with the services that they spoke about. One spoke of an incident with one caregiver who she felt wasn't doing a good job taking care of her mother, but the issue was corrected, and another spoke of how some of the caregivers would continuously invite an Elder out to activities, but the Elder preferred to stay home, but they continued to ask her. The overall response, however, was that the services currently available are good.

Question four: "When a person is seriously ill and is receiving care at home, what do you think are the most important things that community health care service providers should take care of for the person and their family?"

Many aspects of care were named by the Elders. Medication and pain management were considered to be very important. Some Elders discussed medications in general rather than pain medication: "*My mother never took her medication on a*

regular basis. I'd ask her if she took her medication and she would say, 'Yeah', but I didn't know if she did or didn't." (E1)

Other Elders spoke specifically about pain management: "*A nurse came in every eight hours and she'd provide this morphine and she showed him [husband of patient] how to give it to her*". (E2)

Open two-way communication with client and family was important.

"*Well, they sat down with us, and talked to us about how she was doing, how her condition was deteriorating, and I guess, the support*" (E6).

This Elder also referred to the comfort that the families received from the care providers. The importance of personable caregiving was identified by several Elders. "*Bedside manner is very important, and treating our elderly as if it was their mother, or their grandmother*." (E1)

> "*It's about knowing how to treat a person whether they're well* [and] ... *especially if they're ill. They need that extra love and care. That goes so far; it can* [even] *exceed medication…. So going that extra mile, or that extra 15 minutes, I guess I'd say, of kindness* [is valuable]. *Kindness goes a long way*." (E8)

Question five: "Are there any special considerations that health care providers should be aware of when they are providing home care for Aboriginal people?"

Half of the Elders spoke of the need for care providers to be aware of the traditional practices of Six Nations residents who follow longhouse traditions.

"*They should be fully informed on that person, what they like, don't like, and even on ceremonies and stuff. They* [a healer] *may have to perform a ceremony when that care provider is there.*" (E1)

Some of the protocols that care providers should be aware of include avoiding alcohol if you are providing care for a traditional person because it can interfere with the ceremonies:

> "*They have to be told too that, say that person is using medicine, but the health care provider went to a party the night before, and got drunk, or even had a few drinks, and is standing back there on Monday. That destroys that* [traditional] *medicine, so it has to be made quite clear that you* [even as a non-Native provider] *have to abstain from alcohol*." (E1)

Also, women who are on their "moon time" (menstruating) should not be taking care of indigenous people who are not well. This injunction extends even to food preparation. Another Elder commented that he wouldn't want anyone touching his masks:

> "*I belong to the traditional people, and I would not want anybody to be coming in to counteract that stuff, to fool around with them, or anything*. [I would want him or her] *to be respectful of things that are here. I know that there are many things that we do* [or] *we understand* [that outsiders don't]. *And being a native person, we do have priorities* [that may be unknown to non-native people]. *So I would assume that if a*

health care person comes in [that they] *do things in a very subtle way. I wouldn't want anyone to go in there and start cleaning, pick things up, put 'em here, put 'em there. No, no, no, you don't touch them*." (E3)

The theme that emerges is that care providers need to be aware of and be respectful of the traditional practices and beliefs of their clients.

Another theme that emerged is cultural competency in care.

"*They have to approach them* [Aboriginal people receiving care] *in a different way than they do off-reserve, because our people don't talk about things the same way… They need to serve the people in a culturally competent manner, and that means they need to understand, and deal with the person from the perspective of their culture. The person* [who is dying] *shouldn't have to change;* [rather] *the people who are serving need to know how to approach* [them]." (E4)

Another Elder explained: "*Down here, we got two different religions, we got the Christian religion and we got the traditional way. And I think they* [professionals] *should know the traditional way because it's a bit different, because sometimes they* [traditional people] *don't accept help, they'd rather do it themselves. And the Christian way, it's kind of the opposite way*". (E6)

Question six: "I'd like you to think about the system of home care at Six Nations. This would include things you've heard about or experienced. Can you tell me about things that you think are examples of really good care?"

Respectful care was viewed as an important aspect of care.

"*I think the first word that comes into my mind is 'respect'. They* [service providers should] *respect that person, and their life and their ways. That's most important.*" (E1)

Also, the idea of meeting client needs in a caring, personable way was reiterated. "*Well, going the extra mile, and being pleasant when they come in*." (E8)

Question seven: "Now, thinking again about the home care system at Six Nations, what do you think could be improved?"

The Elders were happy with the services currently available and didn't identify anything that could be improved. However, half the Elders did suggest that having more staff and/or more training for staff, including customer service training, would improve the system of care at Six Nations. They also mentioned the need to ensure that all clients on the list receive services in a timely fashion (particularly the need to be on time for appointments). This may be related to the perceived shortage of staff. i.e., if some clients are not being attended to quickly it may be because service providers have a very heavy caseload and have difficulty time seeing all their clients in a shift). Thus, enhanced human resources would improve the system.

Prefaced with an explanation of the purpose of the next questions ("With these next questions, I'm trying to get a sense of what the ideal care situation would be for someone at Six Nations, what perfect care might be. With that in mind:")

Question eight: "When you think of someone in the community of Six Nations receiving excellent care, what would that look like to you?"

The theme that emerged with this question is that individual needs should be met in a caring, personable way. One Elder stated:

"*The ideal for me is feeling safe and secure in my own home, and knowing that they're trying really hard so that I'm not in any pain, and I'm very comfortable*." (E1)

"*Perfect care… I don't know. I mean you can't go beyond caring. Caring for people, whichever way you put it, it's perfect care. To my way of thinking*." (E3)

Question nine: "Who do you think should be providing these kinds of services for people in this community?"

The aim of this question was to assess how important it was to the participants as to whether the care providers are from their own community. All of the Elders thought it was important for care providers to be from the community, though some clarified that they need to be properly trained. They explained that people from their own community would have a better understanding of the people, and that people would simply be more comfortable. The thoughts expressed here: Care should be provided by local community members, if possible.

Question ten: "Where would it happen? (Ideally, where would people receive the care?)"

Six of the eight Elders indicated that the ideal place for people to receive this kind of care is in their home though some acknowledged that because of the level of care some people need, they have to be in a hospital, but the general sentiment was that care at home would be the preferred location.

Important Aspects of Care Identified by Elders

The "Important Aspects of Care" lists that I compiled and then confirmed and modified with the participants are an important source of information for this research. Firstly, many of the Elders did not convey information in direct response to questions, but by bringing up things they felt were priorities. For example, in response to the question: "Are there any special considerations that health care providers should be aware of when they are providing home care for Aboriginal people?", one Elder mentioned the need for a hospice.

> "*Well, a thing brought up at the meeting was a hospice... I think that's what we need here, is a hospice. Because we do have a lot of Natives that are off the reserve, and we just want to come home and if we know that our time is near, I don't know, it's like, I just want to go home to die. Or some of our people went out and never married or had children, but they would like to be surrounded by Natives again. To me, that's home, when you're surrounded by your own kind of people. And you feel more comfortable that way, that you're with your people. So, I would really push for that here, a hospice"*. (E1)

The response is related to the question, but is not in direct response to the question. Thus, the item "A hospice would serve people well" is included in the list, but is not necessarily included in the "response by question" analysis section. This is an example of an item on a list that is only mentioned once in the Elder group, but that is

mentioned several times in the family caregiver group. Below is a table outlining the themes identified from the Elders' "Important Aspects of Care" lists.

Table 1. "Important aspects of care" – Themes Identified by Elders

Theme	Examples
Considerate, caring and personable care	compassionate care, helpfulness, spending time with patients, kindness, positive and caring attitude, understanding, getting to know them, personal, friendly care, and trustworthiness
Good "customer service" skills	putting clients first, being on time for appointments, maintaining a consistent level of customer service
Pain and Medication Management	"A nurse came in every eight hours and she'd provide the morphine and she showed him [husband of patient] how to give it to her" (E2)
Communication with person and family	Elders indicated that they wanted to know about the condition of their family member, and some indicated that they would want to be included in decision-making.
Awareness of and respect for traditional protocols when providing care to Longhouse people.	Care providers should avoid alcohol if they are providing care for a person who is using traditional medicine
Culturally competent care	Knowing how to approach Aboriginal people
Respectful care	"Really good care starts with respect for the person and their family." (E1)
Human resources should be enhanced, both in the number of staff and in the training of staff.	Half the Elders suggested that having more staff and/or more training for staff, including customer service training, would improve the system of care at Six Nations
The Elders stated a preference for receiving services provided by Aboriginal people, particularly by people in their own community	The Elders explained that people from their own community would have a better understanding of the people, and that people would simply be more comfortable.
Care at home should be an option	Most of the Elders indicated that the ideal place for people to receive this kind of care is in their home.
Support for family caregivers	"Instead of being busy with running errands and cooking and cleaning, you can spend more time with them, or just be with them, especially when the time is near". (E1)

Summary of Elder Interviews

As would be expected, there is a great deal of overlap in responses to both specific questions about palliative care and the list of important aspects of care. Below I present a summary list of the combined themes and main ideas.

1. Considerate, caring and personable care
2. Personalized care plans should be developed
3. Pain and Medication Management
4. Open two-way communication with person and family
5. Awareness of and respect for traditional protocols when providing care to Longhouse people.
6. Culturally competent care
7. Respectful care
8. Human resources should be enhanced, both in the number of staff and in the training of staff. The Elders thought wages should also be increased for home care providers.
9. Care should be provided by local community members, if possible
10. Care at home should be an option
11. Support for family caregivers
12. Good customer service skills

Family Caregiver Interviews

The process for the analysis of the interviews with Family Caregivers followed the same format as that of the analysis of the Elders interviews in that I completed analysis of responses to specific questions prior to working with the data from the "Important Aspects of Care" lists. Unlike the strong similarities among responses by the individual Elders I interviewed, there were significant differences in the response patterns of family caregivers. It appears that their situations were very unique. In response to some questions there were no discernible patterns because of the specific experiences these respondents had caring for a dying family member. However, to fairly represent the range of experiences and recommendations for improving palliative care for on-reserve Aboriginal people, I am presenting a summary of all the responses rather than as a set of common themes.

Below is a summary of the analysis by the specific interview questions.

Question one: "What do you remember about the care they (names used) received? What stands out for you?"

The responses to this question varied greatly among the family caregivers. One recalled the availability of staff and quick response to their needs (FC1), while another recalled the late nights caring for their family member. (FC3) Another recalled the difficult situation with care providers who were not available when they were needed (FC6), and several discussed the care and companionship that they provided to their family member when they were ill and outlined the history of the diagnosis and the care required.

Question two: "What things did the care providers do that mattered the most?"

Monitoring the condition of the patient was named as something that mattered most.

"*Just keeping an eye on stuff for us. Like if his temperature went up, they would be there to do whatever they needed to do, give him something, tell him what to try.*" (FC1), and: "*I think just checking on her… and they realized when she was going down, eh?*" (FC4)

Pain management and involving the patient in decision-making were also discussed.

> "*Everything was left to my dad, all the decisions. He never wanted needles, but the time came when he needed a morphine pump. Dr .* "X" *came in and explained to him, 'This is why I think you should have it, but the decision is yours'. And, me, I would have been like, 'No, not my dad, he doesn't want needles'. But he* [the speaker's father] *shocked me when he said, 'Yeah, I need it'. So I knew that he was hurting*." (FC1)

"*They would make sure that he had enough morphine, like, pain medication.*" (FC4)

Question three: "What was least helpful?"

One family caregiver indicated that the lack of scheduled times for nurse visits was an issue for her father.

> *"Well, the only thing… he's a very routine person. He's awake at 5:00, gotta get him washed up and ready to start his day, even though he was confined to a bed or recliner, just the sporadic times that they would come to do what they needed to do. Some days they'd be there at 8:30 which is good, because he's been awake waiting for them, so if they don't come until 10 or 10:30, he'd get crabby."* (FC1)

Another family caregiver said they could have used more help at night "*to give the family a break because we still had to work and go to school"*; (FC4). Thus, consistent timing of visits and keeping appointments, and availability of overnight support, were identified as aspects of care that could be improved.

Question four: "When a person is seriously ill and is receiving care at home, what do you think are the most important things that community health care service providers should take care of for the person and their family?"

The main responses to this question were: Keeping the person comfortable, Pain management, 24/7 telephone availability of care provider: "*I think if you have a need, no matter what time it is, give me somebody to talk to, not pass it off and give me an answering machine. Give me a person to talk to.*" (FC6)

Support for family caregivers and for the patient in terms of relief for care providers, and counselling support for the person who is dying and for the family was also noted.

> "*Support, I think*". [For the family members?] "*Yes, and for the person, cause, like I said, they were both in denial. As much as they talked about DNR* [do not resuscitate order] *and all that, no one came out and said, 'You are going to die'. They always… no one ever says that word, you know. No one ever wants to talk about, or say, 'You're going to die'. And then -- so when you're beating around the bush, you're always giving them* [the family or patient] *that hope, but it's kind of like false hope. So maybe someone that can help the family realize that, when it's in that situation, that he's not going to make it, he's not going to get better. You*

have to plan for some things, maybe in the early stages, what you're going to do in the end, when you need that support all night long". (FC3)

Also noted was that the caregiver may need a bit of time to themselves, so providing relief for family caregivers is important. "*You have to take care of those caretakers. So it would be nice if someone would come and give you a day off once in a while*." (FC2)

"*The* [professional] *care provider should come in and let that* [family] *care provider go away for an hour, if you need to go to the grocery store, or just to get away, providing that the person isn't going to pass on while you're gone*." (FC5)

Communication with family was also noted as important, in general and with respect to options for care:

"*Families are green, really green. Like, going through this, they don't know. They don't know. So any suggestions* [would be helpful], *you know, like: 'I know one family, we did this for them. I know one family wanted that'; you know, 'Maybe this would work; here's an option for you' … any suggestions that they could give* [would be useful]". (FC1)

Question five: "Are there any special considerations that health care providers should be aware of when they are providing home care for Aboriginal people?" Awareness of traditional practices and beliefs was discussed as important.

"*Maybe religious considerations. If they happen to be longhouse, you have to be respectful of their wishes, being that they prefer to be at home*." (FC2)

"*Because some people are Longhouse and they would want to do ceremonies and ask spirits for guidance*." (FC3)

One family caregiver mentioned the larger size of most Aboriginal families, and that all the family members would want to be there when a family person is ill. The respondent suggested that professional/outside care providers should be aware of that, especially when it relates to having several family members visit their loved one in hospital. This idea was reiterated by another family caregiver who stated, "*Our extended families are so dear to us -- in my family, anyway -- when something happens, we all come together and try to help*." (FC7).

The implications in a care setting are that the care providers need to be aware that it is likely that several family members will be present in a patient's room.

Question six: "I'd like you to think about the system of home care at Six Nations. This would include things you've heard about or experienced. Can you tell me about things that you think are examples of really good care?"

Examples that were offered included compassionate care, managing medication, provision of equipment, assistance with housework (in a home palliative care situation) -

"*They would come in and they would take my laundry out, like the heavy things I couldn't do at home, like comforters and that*." (FC6)

Availability of nursing staff was also discussed.

"*They were available when we needed them, when we had to call the nurse. We would just page them, and they would call right back, or they'd come and visit*." (FC3)

Question seven: "Now, thinking again about the home care system at Six Nations, what do you think could be improved?"

Consistent scheduling and attendance of visits was again mentioned.

"*Again, it's the scheduling, because these are their last days, and if you're going to be there at 8:30, you don't call and say, oh, I'll be there at 1:00*" (FC1)

24-hour telephone availability of staff was also again suggested as a way to improve the system.

"*The only other thing we had was, when it got close… if they kept the phone on. That would be one thing I would suggest, is that someone carry the phone all the time. They only carried the phone, when, maybe they thought he was going to pass*." (FC1)

"*Being able to have somebody to talk to, don't leave me a message that someone will get a hold of me. Because you're running around, you don't know. You're scared yourself, and you have all kinds of things going on, and you need somebody to talk to when something is going on. You need someone to answer the phone and talk to you about it*." (FC6)

Human resource issues were suggested as something that could be improved.

"*They could use more workers, to service everybody, so they don't get burnt out. Sometimes they're short-staffed and they get all burnt out.*" (FC7)

Question eight: "When you think of someone in the community of Six Nations receiving excellent care, what would that look like to you?"

One family caregiver indicated:

> "*You know, I think they really do need a facility here where all they do is palliative care, for people that can't handle* [the personal side of care] … *or they have all boys in the family. Men just don't seem to want*

> [to care for the dying] … *or can't handle it. It's not…* [I'm] *not saying their heart isn't in it, but some people can't handle it*." (FC5)

Another indicated: *"A hospice, with full staff; that would probably be the best thing, I think. But it would be the client's choice, too, to use it or not."* (FC3)

> "*I don't know if it's possible or not, but I think it should go back to the person's wishes and what they want. Do they want to be home* [or] *do they want to go to the hospital? Then those wishes should be granted. If they know they're dying, why should we be telling them what to do? We should be listening to them."* (FC7)

Consulting with patients about their wishes was considered important, along with providing a hospice in the community.

Support for family members was also noted as something that Six Nations people need. A family caregiver again explained how difficult it was for the family members to discuss the illness and the fact that a loved one was going to die soon. (FC3) Another person explained,

> "*I've heard about a few families where their family* [member] *has died there* [at home] *and they panic. And there's nobody there and they're calling and saying, 'Oh, my god, this is happening, what do we do?' There was no preparation for the family, -- like, 'This is what is going to happen. Are you able to handle this?' -- kind of check with them. I think they're just as important to be looked after as the client*." (FC7)

Thus, counselling for palliative patients and their families should be available was yet again brought up.

Question nine: "Who do you think should be providing these kinds of services for people in this community? "

Most of the family caregivers indicated that they thought the professional care providers should be from the Six Nations community, although there were some that said it didn't matter. *"Anyone. Anyone can provide this kind of care. Native or non-native, anyone, as long as they ask the family what the person wants*". (FC5) "*It doesn't matter to me. As long as I have help, I'm happy.*" (FC6)

Question ten: "Where would it happen? (Ideally, where would people receive the care?)"

The response was overwhelmingly "at home".

"*Probably in their home. Cause that's where they are most comfortable"*. (FC3)

"*For the person that is passing away, I think they would be more comfortable in their home"*. (FC5)

Thus, care at home should be an option.

Important Aspects of Care Identified by Family Caregivers

As in the analysis of the Elders "Important Aspects of Care" lists, were developed following the analysis of the responses by question. What follows is a summary of the analysis of the "Important Aspects of Care" identified by family caregivers.

Table 2. "Important aspects of care" – Themes Identified by Family Caregivers

Theme	Examples
Monitoring condition of client	*"Just keeping an eye on stuff for us."*
Pain Management	Medication management; pain management
Involving client in decision-making	respect the wishes of the patient with respect to care plan and involve family in their decision-making;
Consistent timing of visits and keeping appointments	make every effort to maintain a regular schedule with home visits
Availability of overnight support	Family members may need support at all times; 24/7 support for family members
Keeping the person comfortable	ensuring the physical comfort of the patient
24/7 telephone availability of health care provider	24/7 availability of care provider by phone; especially when the person is nearing the end
Counselling support for the person who is dying and for their family	counselling for the person who is terminally ill on coping with their diagnosis; counselling for family members to help them cope with loss
Providing relief for family caregivers	assistance for families in providing care; support for families in providing care (i.e., provide relief)
Communication with family	regular communication with family about care plan and the person's condition; open and timely communication with family
Awareness of traditional practices and beliefs	being aware and respectful of the family's traditional beliefs and practices and what is expected of them as a caregiver
Provision of equipment	providing equipment to family; access to appropriate equipment
Assistance with housework	help with cooking and cleaning so that family caregivers can take care of patient
Hospice is needed in the community	A hospice on the reserve would be good; homes don't have the basic amenities in providing care
Care at home should be an option	Care in the community allowed for a better experience compared to a hospital – "Indian humour" at home made a big difference
Respectful care	allow the person to maintain their dignity; respectful care
Personable, caring care	providing "caring" care; being friendly
Financial assistance for families who need it	access to medical transportation for appointments
Local care providers are preferred	Aboriginal care providers are preferred as they understand their own people and have insight into things that would take an outsider years to grasp

Summary of Family Caregiver Interviews

As with the analysis of the Elder interviews, there is a great deal of overlap between the two sections. Upon analysis of both the responses by question and the "Important Aspects of Care", a summary list outlining the combined themes and main ideas was developed and appears below.

1. Monitoring condition of client
2. Pain Management
3. Involving client in decision-making
4. Consistent timing of visits and keeping appointments
5. Availability of overnight support
6. Keeping the person comfortable
7. 24/7 telephone availability of health care provider
8. Counselling support for the person who is dying and for their family
9. Providing relief for family caregivers
10. Communication with family
11. Awareness of traditional practices and beliefs
12. Provision of equipment
13. Assistance with housework
14. Hospice is needed in the community
15. Care at home should be an option
16. Respectful care
17. Personable, caring care

18. Financial assistance for families who need it

19. Local care providers are preferred

The family caregivers discussed a number of aspects of care that many of the Elders did not, though there was considerable overlap between the two groups. As is shown in the table below, the types of issues they spoke about that the Elders did not were related to the manner in which care delivery was experienced by them in the care of their family member. For example, they spoke of provision of equipment, availability of overnight support, 24/7 telephone availability of care providers, the need for counselling support for the person who is dying as well as the family, and the need for a hospice in the community, though one Elder did also mention the need for a hospice.

Table 3. Themes by interviewee group

Themes Identified by both Elders and Family Caregivers	**Themes only Identified by Elders**	**Themes Identified by Family Caregivers**
Considerate, caring and personable care	Personalized care plans should be developed	Monitoring condition of client
Pain and Medication Management	Human resources should be enhanced	Consistent timing of visits and keeping appointments
Open two-way communication with person and family	Good customer service skills	Availability of overnight support
Respectful care		Keeping the person comfortable
Culturally competent care		24/7 telephone availability of health care provider
Local care providers are preferred		Counselling support for the person who is dying and for their family
Care at home should be an option		Provision of equipment
Support for family caregivers		Assistance with housework
		Hospice is needed in the community
		Financial assistance for families who need it

Elder and Family Caregiver themes and subthemes

From the resulting Elder and family caregiver lists, which combined, included 22 items, it was clear that some of the items, though distinct, were related. Thus, these items were categorized further, with the related items grouped together under a heading that encompassed items that were classified as subthemes. The following table outlining the main themes and related subthemes was developed.

TABLE 4. IMPORTANT ASPECTS OF PALLIATIVE CARE AT SIX NATIONS

Personable, Caring Care

• Respectful care
• Personalized care plans should be developed
• Counselling support for the person who is dying and for their family
• Seeing client as "customer"
  o Good customer service skills
  o Consistent timing of visits and keeping appointments

Culturally competent care
• Awareness of traditional practices and beliefs • Local care providers are preferred
Open two-way communication
• Involving client in decision-making • Communication with family
Support for Family Caregivers
• Availability of overnight support • 24/7 telephone availability of health care provider • Providing relief for family caregivers • Assistance with housework • Financial assistance for families who need it
Care at home should be available
• Provision of equipment (to enable care at home)
Meeting comfort needs of person
• Monitoring condition of client • Pain Management • Keeping the person comfortable • 24/7 telephone availability of health care provider
A Hospice is needed in the community

Palliative Care Provider Focus Groups Analysis

A number of themes emerged from the focus group discussions with health care providers. The main theme revolved around relationships and the rapport between the provider organizations, with a number of related subthemes. Other themes include cultural considerations in care and broader system factors that influence care. As all of the organizations have unique roles, strengths and challenges, these are outlined under "Within-Program Strengths and Challenges" and listed by organization following the description of the theme and subthemes related to relationships and rapport.

Relationships and Rapport

The main theme that emerged from the focus groups was Relationship/Rapport Issues. Each focus group involved a significant amount of discussion on the interaction of the different care provider organizations. Respondents from each organization acknowledged that there are challenges with respect to the relationships among service agencies and that they are working on resolving or reducing the impact of those issues, which included the following:

- Communication
- Lack of Clarity on Roles
- Jurisdiction
- Relationship Building

Communication. Communication was reported to be an issue. During the (CP/FNN) focus group, when asked what the challenges were, a reply was

> "*Communication is the big challenge. When you have two different people going in there, us and Six Nation LTC/HCC, it's just, nobody knows who to turn to when there's a problem or a crisis, and they* [Six Nations LTC/HCC] *just panic, and start calling us right away, and think we're going to go there and fix the problem, you know, that's a huge challenge.*" (CP/FNN nurse)

CCAC case managers also discussed the communication challenges. One example is so compelling as to be worth duplicating in its entirety, below:

> "*I think it's communication that's the big problem, because often times you don't quite know -- like, when we first started back into doing Six Nations palliative care, I was trying to figure out, 'Okay, what does Six Nations home support, or long term care ... what do they manage? What do they do? Okay, they do this. Then you've got your visiting nurses, but then sometimes their nurses might go out to see somebody in Jay Silverheels' [name of the long-term care/supportive housing facility operated by SN H&CC]. And, you know, it's confusing to know who the players were and how they fit in. I knew what the visiting nurses did, but I didn't quite understand the whole spectrum of what the Six Nations long-term care can do in the community. So communication is the key, the key*

between the nursing agency and the LTC and how that works, that's the important thing."

Another CCAC case manager stated: *"... I have had two very difficult deaths recently, and unfortunately, it has been around communication. It's been around whose responsibility it is to do what, who can we then yell at or blame for a situation gone awry; instead of how can we fix it*".

A third case manager added: "*It's very subtle, it's suggested, either by Six Nations long-term care or suggested by First Nations* [Nursing], *I don't think that there's anything that we could say... "they don't communicate", but certainly, both sides are telling us they don't communicate with each other, so, there's that underlying "he said". Or, "she said, she said", it's very subtle*."

Lack of Clarity on Roles. An important theme in all the focus groups was the lack of clarity about the roles of the different provider organizations in the community, both for the care provider organizations but also for clients, as well.

Case managers in the Six Nations HCC focus group explained that there is confusion about the roles of the different provider organizations.

"*Clients don't know who does what, who belongs to who, so they call whoever they know has been helping them, we tell them "X" is your case manager, so they will call us, and if another agency is involved, something*

should be set up so that the clients know who to call, and maybe FNN should explain what their role is."

Nurses in the Care Partners/FNN focus group also expressed frustration with the same issue. "*Clients are given so many phone numbers, they don't know who to call*".

The CP/FNN nurses suggested that it seems to be the case that the PSWs [Personal Support Workers] have unrealistic expectations of what the nurses can do. It sometimes appears that they think that: "*The nurse will come and magically fix everything.*"

The CP/FNN focus group provided an opportunity for the nurses to learn about the role of the PSWs and a few misconceptions were cleared up over the course of the discussions. One of the CP nurses explained that the role of the PSWs is to observe and report, not to make assessments. One of the nurses reported that she knew that some of the PSWs are taking the palliative care course, and they were hopeful that it would make a difference, once they had a better understanding of the care of palliative patients. "*I think once they understand what's going on, it will be better*."

Another CP/FNN nurse commented that some of the PSWs do have skills but they aren't allowed to use them.

"I found with the PSWs, they do have knowledge and skills, but they're held back over there, they're not allowed to use those skills, and it does cause them to panic, because they do have this bit of knowledge, but they can't use their skills because the case manager says they can't use those skills." The example given was changing catheters.

One of the CP/FNN nurses explained that some responsibilities can be delegated to PSWs, but only in specific situations. If a PSW is trained to change a catheter for a specific client, they can do it for that client, and that client only. This was new information for the nurses, and appeared to broaden their understanding of the role of PSWs. *"OK, there you go, we've learned something about why they can't do it"*.

Jurisdiction issues. The lack of clarity of the roles held by each of the organizations was discussed extensively in the focus groups and it became apparent that the issue of jurisdiction is a challenge in providing care. A CP/FNN nurse pointed out that there is a sort of dual case management going on, which she suggested inevitably causes conflict. The Brantford CCAC oversees nursing services that are provided in home, while Six Nations LTC/HCC case managers oversee PSW services. Very often in palliative cases, both organizations have staff providing services in the same home. "When there is a crisis, people don't know who to turn to, and they start calling everyone they can." In the Six Nations LTC/HCC focus group, one participant asked: "*Who is in charge?"* A response from another participant was:

> *"Technically, it's the CCAC because of the level of care that's needed, but if CCAC says they've done what they can do... well... we kind of care, I guess you'd say, we wouldn't shut the door" ... when you're in the community, who is the leader then?"*
>
> "*Sometimes it's just those unforeseen circumstances that lead up to.... whatever. And you end up dealing with it. But it helps to know who to call, and what people*

do, and who is responsible for what. But when there is nobody, then it ends up back with you."

The question of "who is in charge in the community?" is a significant challenge to the community providers, particularly to Six Nations LTC/HCC. In the past, Six Nations LTC/HCC staff members have tried to initiate care for clients by calling CP/FNN. These calls were not well received by CP/FNN. The CP/FNN nurses outlined a history of appropriate pathways not being followed by Six Nations LTC/HCC staff. That is, Six Nations LTC/HCC staff members have called CP/FNN to request services, but they explained that it is not an appropriate process. They should be contacting CCAC directly, who in turn would contact CP/FNN. However, by April of 2011, this issue was reported to be resolved, possibly as a result of enhanced communication.

In the Six Nations focus group, the case managers explained that at times, the nurses at FNN are required to see clients at Jay Silverheels, and

"*It seems like they feel they are treading on our territory, but we don't see it that way – we see it as a client with needs that have to be met, wherever they are. So that needs to be cleared up."*

The issue of the CP/FNN nurses and Six Nations LTC/HCC PSWs providing services in the same home was discussed in the CP/FNN focus group. i.e., they try to space out the visits and ensure that they are not there at the same time so that the client support is spaced out. Protocols about calling the nurses were discussed, and the group agreed that if a PSW felt that the patient was suffering and needed to be seen by a nurse, that it was acceptable for them to recommend to the family members to call the nurses, as

the clients or family members could call the nurses anytime. The issue for them in the past was that the PSWs were calling them directly, and it was pointed out that the clients may not always want what is being recommended by the PSW.

Relationship Building. Focus group participants from all the organizations indicated that since 2009, (when data collection for this project began) efforts have been made by all parties to improve communication and collaboration.

> "*The relationship building that has been happening with Six Nations LTC H&CC in the past year is a strength to the system. Meeting with them on a regular basis is helpful, there is still room to grow, but it's been a good start.*" (CCAC case manager focus group)

One of the main improvements was the implementation of weekly rounds held at Six Nations with Brantford CCAC case managers, and later, with the Care Partners/First Nations Nursing organization represented. Including the latter organization in the weekly rounds commenced after the focus group with the CCAC case managers in May 2010. A CCAC case manager indicated:

> "*One of the challenges that I've found is that it would be helpful to have nursing at the table, as well... We can certainly call them on a case-by-case basis, but not on a... when we go out to meet with Six Nations, it's [Six Nations] Long-Term Care, it's not everyone on a regular basis.*"

In the September 2010 focus group with the CP/FNN nurses, they confirmed that they are now participating in the weekly rounds with SN H&CC and CCAC case managers, and that a number of things are being introduced, i.e.,

> "*CCAC care pathways, best practice guidelines, related to wound care, and helping them understand that if a doctor puts a client on service for daily wound care, that doesn't mean they will receive daily wound care, because it might not be a best practice order*."

Within-Program Strengths and Challenges

Brant Community Care Access Centre (CCAC). CCAC internal changes have enhanced the provision of palliative care services with the CCAC designated palliative care case managers now overseeing the palliative care cases at Six Nations. Prior to this change, the case manager assigned to Six Nations managed all of the Six Nations cases, including palliative cases.

> "*Instead of a general population* [case manager] *dealing with palliative clients, the move has been to have the experts deal with palliative clients, which therefore enhances the access, because they're dealing with people who have the expertise of palliative care*."

A challenge that CCAC case managers expressed was the distance to the reserve and the workload experienced by the case managers.

> "*If we're going to be honest, I think, sometimes our workload prevents a higher profile of us being out there as often as we'd like to be, you know,*

we've got heavy workloads, and you know you've got a client on the reserve and a client here, that are both really needy, and you've got a half hour, you're going to do the one in Brantford before you're going to get to the one on the reserve, you're going to get to the reserve the next day maybe, because you're going to plan it differently, but if you've got that type of thing, I mean, yeah, that's... to be honest, that does happen."

"… which would be eliminated, if... it was its own little, sort of, specialty, in having a case manager there, even if it was 2 days a week, or 1 day a week… so workload, I think, is a barrier, I think the other thing, to piggyback onto the workload, is the overarching goals of the CCAC and, doing things a little differently, so we need to get management or senior leadership approval to work things a little differently and so far we don't have that... the idea of being there one day a week makes sense to me, don't have to be there all the time, but one day a week..." [would be a good idea].

This idea of having a Brant CCAC case manager at the reserve one day a week hasn't become a practice of the Brant CCAC, though as of May 2011, they do continue to participate in regular meetings with Six Nations Home & Community Care and First Nations Nursing/Care Partners to discuss Six Nations clients.

Six Nations Long-Term Care/Home & Community Care. A strength identified by the case managers is that the Manager of Six Nations LTC/HCC is participating in the different network meetings, i.e., the Hospice Palliative Care Network.

"...at those meetings we get an opportunity to express our concerns or any issues we have, and the support at those tables help us, give us ideas on how to deal with issues that come up."

Another strength of the program is the level of commitment by staff to provide good care.

"The family is looking to us to help them because they did already try everybody else, and they weren't getting any answers. So rather than say, oh, that's their job, we kept at it until we knew there was a resolution to it. And that's primarily what our role has been. To be that support to the family."

Six Nations LTC/HCC case managers explained how community members will call their organization when they are in need, and that they sometimes encounter clients that are, in fact, in need of palliative care services.

"*I think they all rely on us. Even the clients, they all call us when they want something. So it's up to us to assign a case manager and figure out where we're at in the whole system. Or it might come through on a different service, like, if [a social worker] is out seeing them for a totally different matter, like say pension or something, they might become aware of, that they're near the end of their life, so it still has to come back, so we*

can pick up referrals in other ways too. And somebody said earlier, sometimes you don't know you're in a palliative situation and we even admitted a person into Jay Silverheels for a respite and it turned out to be a palliative situation."

Limited human resources was seen as a challenge for palliative care services at Six Nations.

"*We have a high demand just in general for our existing clients, because of the need in the community, and when... it's not necessarily a burden, but when you add a palliative situation, and you might get one or two or three at a time, then it's just very difficult to try to balance where you don't have someone going without on the regular roster, to add in the palliative, it's difficult to balance, but we always... even though we don't have additional resources, we do consider palliative a priority.*"

"*We wanted to put in a discharge planner, or coordinator, who would kind of be like our 5th case manager, and they would handle those complex cases, and they would handle the discharges, if they knew somebody was in hospital, they're coming home with a new diagnosis of cancer, then they could help [the case managers], to get that all set up… but I don't know that it's going to be supported the way that we wanted it. But even that, the idea of creating new roles and responsibilities needs to be supported right up the line, and with Home and Community Care, each year that we do our report, every year for the past ten years, palliative*

care has been an issue, and there's been no attention paid to it. There's been a little bit of research off and on, a little bit of training, that kind of thing, but nothing to address the need in the community."

Palliative care training for the PSWs was identified as a need. They explained that they need "*people that are well-trained and experienced in those situations.*"

Discussions at the HPCN Aboriginal Hospice Palliative Care committee meeting revealed that the Fundamentals of Hospice Palliative Care program offered by the Hospice Palliative Care Network is not seen to be culturally appropriate for Aboriginal communities, and discussions have been ongoing to modify the program so that it would be more appropriate for use in First Nations, but this has not happened to date.

Prior to the evolution of the health care team at Six Nations, one of the physicians was on the home care team, but that isn't the case anymore, and this was identified as a challenge. The case managers felt that having a local physician available if they should run into an emergency situation would help to avoid some of the negative experiences they have dealt with recently in the care of a palliative patient.

Dealing with grief after the passing of a client was discussed by the case managers.

"We're expected to go back to work immediately, and that's not part of our culture. You're supposed to set that time aside and allow for that grief, and you cleanse yourself off and come back, not just, "it's part of your day" kind of thing... and that's the kind of thing our policy promotes. It's not conducive to the grieving process, or even our culture, so people

have problems with that emotionally, and I think some people can just get back to work and I think sometimes it helps them, distracts them, but others come back and they can't focus."

The Six Nations LTC/HCC case managers indicated that they would like to have their own shared care palliative care team.

"*That is going to be our next step, you know how they had those town hall meetings, we decided that SN will have their own, and then it would be the start of a shared care team. We have some things already here. We're just building on it.*"

"*We talk about shared care teams, and there's always a physician on that team, so I think if we had a designated physician that could take the lead on the palliative team, that would definitely help us*."

Care Partners/First Nations Nursing. In the CP/FNN focus group, a CP nurse explained that the Care Partners/First Nations nursing organization underwent significant changes when the First Nations Nursing organization was purchased by Care Partners in late 2008. The organization was previously owned by an independent owner of the single nursing organization located at Six Nations. In the Brant CCAC focus group, the case managers discussed the transition and explained that there were challenges in the process.

"*There are definitely, how do you say... difficulties between FN, that core group and the Care Partners... like X said, it's an outside agency coming to try... and there are problems there... they're trying to work on them*".

"*I would say, you know, 8 months ago, it was not nearly as good as it is getting... I see it better and better all the time. And certainly at that table I was at last week, there was lots of conversation between X and the nurses at the table... I saw it as being a very good relationship. I think they're really headed in the right direction.*"

It was explained that the transition happened at a time when there were a lot of changes happening in health care, at CCAC, and at the LHINs, so the nurses had to deal with a lot at one time.

In the focus group with CP/FNN, the nurses discussed the adjustment they had to make from working for the previous owner of First Nations Nursing and now working for Care Partners. It was a significant change for them and they are still adjusting. One of the nurses acknowledged that they have had to "*pull up our socks a bit, and get better at more education and paperwork*".

The nurses were asked if they were over the "hump" and one replied that they were "*hitting the peak, I think*". There was laughter, but they explained that there was still a lot for them to learn: "*It's just so many levels of information you have to learn, it's a ball that's ever turning, and you just have to keep up with it*."

The nurses acknowledged that their skill levels have increased with the training they have received from Care Partners.

The group discussed the current challenges in the overall system of care at the provincial level, with lack of funding for home care, and for hospitals – which results in

patients being sent home earlier and with more serious conditions, thus putting more demands on the needs for nursing home care and for ongoing skills development.

Educational opportunities within Care Partners were identified as a program strength.

"*Care Partners offers many different avenues for training of their nursing staff. Inservicing, education opportunities, a clinical nurse educator is available for each division. Care Partners is a best practice spotlight candidate organization through RNAO [Registered Nurses Association of Ontario], so we do a lot of work implementing best practices. All the CP/FNN nurses have either completed or are in the process of completing a palliative care program*".

Another identified strength was the strong teamwork environment with good communication amongst the nurses, and that they are helpful and supportive of each other. "*We can just come back here and bounce things off each other, you know, how would you do this, or that. It's helpful to have people to talk with about things*."

The nurses also felt that one of their strengths is that the nursing staff is from Six Nations, and that the clients appreciate that. They also felt that people have come to know CP/FNN as they've been here a long time and that people trust them to come in and provide their care.

One of the CP/FNN nurses explained:

"*It's kind of like, everybody is your family, and you know them all, or their family, I think we give them a lot of extra, than other people would*."

A Care Partners nurse (not from the reserve) indicated that it does seem to be different on the reserve, that the nurses here: "*do try to go over and above, to achieve the goals in the level of care that they feel that they deserve. And that's different*."

The nurses noted that it was important to review with families what their options are and to make sure they really understand what is going to be required of them. The nurses come in daily, but the family is going to have to do a lot of the care giving themselves, and sometimes it's too challenging. They discussed how some family members get worn out, but they are resistant to having a PSW in the home to help them. They suggested that in the case of a family who has refused PSW help, that it might be a good idea to remind them that the PSW service is available to them after they go it alone for a while, and to encourage them to get help. The nurses also identified patients not being aware of their palliative status as a challenge.

The option of having a case conference with families was discussed. Not many case conferences have been held, but it is an option that they might consider more often, when appropriate.

The CP/FNN nurses had a discussion about how some of the clients would prefer to have the same nurse come to see them all the time, but they agreed that in palliative cases, the burnout rate is high, and that it was better for the nurses to share the caseload, but that in those cases, it was really important to make sure that the nurses are communicating with each other about those clients.

Another issue the nurses have encountered is family members who request grief counselling but it hasn't been available from Six Nations Health Services in a timely manner.

Cultural Considerations in Providing Care

In the CP/FNN focus group, the nurses discussed the benefits of having Aboriginal care providers providing palliative care services within their own community.

> *"On the reserve, there is a true understanding of the culture by the providers, as opposed to off reserve, where you can teach nurses about different cultures, but there isn't a real understanding, but here, really, it's lived, more so than just talked about*."

Six Nations LTC/HCC developed an initiative with the Six Nations Traditional Wellness Coordinator and a Six Nations Elder to develop a resource manual and training program for local care providers. The resource manual and training program were designed to provide teachings on death and traditional practices of the Haudenosaunee. The PSW staff members that have received the training thus far enjoyed the training and the benefit of having an Elder available to answer their questions related to care of a traditional person who is in their last days. The Six Nations LTC/HCC case managers felt that other health care providers at Six Nations would benefit from this training.

Six Nations LTC/HCC staff indicated that they do not feel that they have a role in providing access to traditional healers.

"*It is the family's role to take care of any traditional protocols as it relates to death. It's a challenge sometimes because every family is different, and sometimes you have some family members who are longhouse and some that are church, and some that are neither*".

Though it is not perceived to be their role in facilitating access to traditional healers, they felt it was very important for care providers to be aware of traditional protocols that might be taking place.

One case manager suggested that allowances should be made so that staff may practice traditional protocols, i.e., it is a traditional practice to cleanse before returning to normal activities. "*Workers should be able to go home and change their clothes and cleanse after someone has died*".

Broader System Factors that Influence Care

Both community organizations discussed the issue of palliative patients being discharged from hospital without an appropriate care plan in place. In one instance, the patient had no family doctor.

"*So the client comes home, we've got nobody to follow up for pain control, pronouncement, for any issues that come up with the client, and it's... the whole thing has fallen apart before we even got started*."

The CP/FNN nurse manager suggested that there should be some criteria for hospital staff discharging a palliative client, before they can discharge them.

"*If I'm discharging a palliative client, here's the top 10 things that must be in place and double-checked to make sure that it is before I can send them home with their families.*"

Both community organizations also discussed how family members of a palliative client being discharged from hospital are not always prepared to take care of their family member at home. They expressed concern that no one in hospital explained what their role in taking care of their family member at home would be and they are then upset when the nurse or PSW are only in for brief periods. "*They want us to be there 24 hours a day, and look after them, the way they do in the hospital*."

A Six Nations LTC/HCC case manager pointed out that there are also other parts to the system that need to be considered. Pharmacies and companies that provide equipment play a role in a palliative case, so the case management role is an important one.

Chapter 5: Discussion

This interpretive qualitative case study examined the system of palliative care service delivery at Six Nations of the Grand River, a First Nation community in southern Ontario. The large on-reserve population, the close proximity to an urban centre and the existence of a private First Nation-based nursing provider make this a unique system of home-based palliative care service delivery in the province.

Despite the uniqueness of this system of palliative care, many of the findings in this study are in keeping with the literature on Aboriginal palliative care, both in the Canadian context and in international Indigenous contexts. Similar findings have been reported with respect to a need for culturally competent care, respectful care, open communication, shared decision-making with respect to care decisions, and a preference for Aboriginal care providers in Aboriginal communities. The national initiatives outlined in the literature review of this thesis also report findings similar to this study. In particular, the identification of jurisdictional challenges at the local level at Six Nations reflect the issues that exist at the national and provincial levels in Canada, and the need for culturally relevant care and training of Aboriginal care providers.

Given the jurisdictional issues inherent in the Aboriginal health care delivery system in Canada, it is not surprising that there are unique challenges within this system of care. At the outset of the project, Six Nations LTC/HCC staff identified issues within the system, particularly a perceived lack of access to culturally relevant, person-centred and timely primary palliative care services for their clients.

The stated objectives for this research project were to: assess how various stakeholder groups within the Six Nations community define person-centred palliative care; determine the degree to which services currently offered on the Six Nations reserve enabled that to occur, and obtain recommendations on how to improve palliative care services currently being offered to the Six Nations community.

Table 4 is a summary of the findings from Phase I of the research project that assesses the system of care from the perspective of Elders and family caregivers, and outlines the important aspects of care from their perspective, which include some recommendations on how to improve the system of care.

A Six Nations LTC/HCC representative, following the completion of the analysis of the interview data, expressed appreciation for the findings and indicated they were going to address the issues even before the final report was completed (August 2010 palliative care research meeting).

The focus groups with care providers revealed a system of care that has evolved over time. At the outset of the project in 2008, Six Nations LTC/HCC staff reported that there was little in the way of communication among staff working at First Nations Nursing, Six Nations LTC/HCC and the Brant CCAC, although there was more (albeit intermittent) contact between the latter two organizations (Oct. 2008 Hospice Palliative Care Network Aboriginal Hospice Palliative Care meeting).

The focus groups took place between April 2010 and September 2010. By May of 2010, when the CCAC focus group took place, they reported that they had begun meeting with the Six Nations LTC/HCC case managers on a regular basis, and that the CP/FNN

nurses were not meeting with them but that they should be invited to meetings. The CP/FNN focus group took place in September 2010 and they reported that they were now attending the meetings with the other two organizations, and that the roles of each organization were becoming clearer, due, in part, to knowledge sharing that was taking place at these meetings. The nurses learned more about the role of the SN H&CC case managers, i.e.,

> *"They don't do hands-on nursing, but they make sure that nursing is in, do they need PSWs, are they getting enough PSW support, are there other things that they have to look at, so now with these meetings every Thursday, we go through the caseload of every client, and we talk about the client, and if their needs are being met, what's CCAC's piece, what's their piece, so that's kind of where we are now."* (CP/FNN nurse)

Similar thoughts were expressed at a September 2010 HPCN AHPC meeting by a LTC/HCC case manager who indicated how good it was to now have CP/FNN at the table and explained that they had recently had a case conference with them and how important it was that they were now communicating with them about the clients that both organizations were seeing. A personal communication (email) from a Six Nations LTC/HCC representative shared her thoughts on the focus groups:

> *"I think we should identify how the positive changes occurred through open communication and awareness of the situation as they came up – participatory research. These are very significant changes that needed to occur and did occur as a result of the research (focus groups) and*

involvement of a person such as yourself who was non-judgmental but able to identify areas which required "attention". The other major catalyst was the fact that LTC/HCC was able to report an incident/occurrence/ concern to someone who would listen and offer to make a change – whether it be you, [X], [X], or the network." (SN LTC/HCC representative)

This email was sent to me as feedback from the focus group report and is included here to share the perspective of one (and only one) of the people who participated in the research process. This feedback was not solicited, however, from this participant or from any of the others, so I must acknowledge that it may not represent the views of all participants.

In any event, the idea that a "non-judgmental" or neutral party could facilitate positive changes in jurisdictional challenges is an interesting one and may have application in other relevant situations. A Six Nations LTC/HCC representative reported that through a network of other Home and Community Care representatives across Canada, she learned that some CCACs do not provide services on reserve, even if they are within driving distance. One reason given was that the CCAC felt on-reserve care was a federal responsibility. Clearly, as the Brant CCAC does provide services on-reserve, there is not a clear policy for CCACs with respect to providing on-reserve care.

Hanson and Associates (2007) comment on the issue as follows:

> "*The two levels of government – provincial/territorial and federal – both attempt to be the "payer of last resort" in attempt to control costs and shift as much of the burden as possible to the other government*." (p. 19)

Hanson and Associates also report that the lack of case coordination and management between federally funded on-reserve primary care and provincial/territorial acute hospital service providers is a serious gap. The example of poor discharge planning support for Inuit returning to their home communities from urban hospitals and not receiving appropriate pain management options was given. This same issue was reported at Six Nations by both CP/FNN nurses and by Six Nations LTC/HCC.

Hamilton Niagara Haldimand Brant Hospice Palliative Care Network

The Hamilton Niagara Haldimand Brant (HNHB) Aboriginal Hospice Palliative Care (AHPC) committee was formed from the larger HNHB Hospice Palliative Care Network (HPCN). The committee started meeting in November 2007, and I started attending in February 2008, their second meeting, and I attended regular meetings until 2011. The mandate of the committee is to work with all key stakeholders to improve Aboriginal Hospice Palliative Care throughout the HNHB Local Health Integration Network (LHIN) area.

Since the inception of this committee and this research project, there have been a number of significant milestones. As already described, regular meetings with all the care providers now take place. Also, networking with other Aboriginal palliative care researchers in Ontario took place with sharing of knowledge and resources and a joint

submission of a CIHR Intervention research grant application on Aboriginal palliative care that was successful and received funding in 2010. The grant was awarded to Dr. Mary Lou Kelley of Lakehead University and Dr. Kevin Brazil of McMaster University. I am a co-applicant on the grant and I participate in ongoing activities related to the project. The $1.8M grant is to fund a 5-year project aimed at increasing community capacity to provide palliative care services within the communities of Six Nations of the Grand River, Fort William First Nation, Naotkamegwanning First Nation (all in Ontario), and Peguis First Nation in Manitoba. The project will employ a Community Facilitator in each community. The Six Nations Community facilitator was hired in January 2011 to work with local service providers on the project. This comparative case study augments and builds upon the research project described in this thesis. It is very likely that the Six Nations system of palliative care will gain significant benefits from partnering in this collaborative research project. In particular, the development of a local Six Nations palliative care team is likely to take place with the support of the Community Facilitator and research team.

Also during the time frame of this research project, the HNHB Hospice Palliative Care Network was hosting "town hall" meetings throughout the LHIN, and the AHPC committee decided that they would host an Aboriginal specific town hall meeting, though they chose to call it a strategic planning session on Aboriginal Palliative care as they felt the term "town hall" wouldn't resonate well with the Aboriginal community. The event took place on December 2, 2010, at Six Nations. More than 60 palliative care providers and community members attended. I participated in the planning and organization of the

event. Representatives from the CCAC, Six Nations Health Services, Hamilton Health Sciences, McMaster University, Lakehead University Centre for Education on Research and Aging in Health, and other groups made presentations. Dr. Denise Marshall, Director of the Division of Palliative Care, McMaster University, presented information on a shared care model of palliative home care delivery that is described below.

Shared Care Model of Palliative Care

Marshall (2008) describes a model of shared care to enhance family physicians' ability to deliver quality palliative home care, particularly in a community setting. As an example, she cited the work of an inter-professional palliative care team (comprised of a palliative care advanced practice nurse, palliative medicine physician, a bereavement counsellor, a psycho-social-spiritual adviser, and a CCAC case manager) that collaborated with three family physician group practices in the Niagara West region of Ontario to provide comprehensive palliative home care. The physicians received training and support from the palliative care team, yet were still the professionals most responsible for providing patient care.

There would be many benefits to such a shared care team model being implemented at Six Nations. First, services would be more integrated, thus avoiding some of the difficulties that participants in the current research project have reported occurring at the Six Nations reserve. As one CCAC case manager acknowledged:

> "*We have had some bad deaths -- that's the elephant in the room, right? -- we have had some bad deaths. And, we have had to really*

examine -- and they have, too [Six Nations LTC/HCC] -- the process. We are meeting again this week or next week with them. And I think that it really does have to do with communication. We don't want these things to happen, but when they are happening, we are on it. … whether it's on our side, or whether it's on their side, we have a process that is able to look at some of these events in a really not judgemental [way]*, but in a: 'Let's see what we can learn from this; what are the lessons learned* [way]*' and then move forward*."(CCAC case manager)

Another benefit of a shared care model would be the elimination of the confusion about who to call when a crisis is encountered. Six Nations LTC/HCC program staff members have expressed a desire for such a team at Six Nations. Six Nations currently does have access to the Brantford Palliative Care Team that is available through the Stedman Hospice in Brantford through CCAC case management, thus providing access to "expert" palliative care physicians, a key component in Marshall's shared care model. Six Nations LTC/HCC program staff reported that prior to the Family Health Team being established at Six Nations, they had a physician on the home care team, but that is no longer the case as 100% of the physician's time is allocated to clinic hours. The Six Nations LTC/HCC program has some of the "pieces" of a shared care team already available, but some of the critical pieces, i.e., a physician, are not in place. However, they have proceeded to form a palliative care team within the Six Nations Health Services staff currently in place, including case managers, personal support workers, social workers, and the traditional wellness worker.

Kelley's (2007) conceptual model for developing rural communities' capacity to develop palliative care discusses the antecedent conditions that are necessary in a rural community to facilitate the development of palliative care in the community. Though the model was developed for rural communities, it is relevant here. Two of the antecedent community conditions named in the model include sufficient health services infrastructure and a vision for improving care to dying people. These two conditions are certainly present at Six Nations. The focus group data demonstrate the commitment to quality care by the community providers employed by the LTC/HCC staff. The statement *"...we kind of care, I guess you'd say, we wouldn't shut the door."* is telling of that commitment and the desire to be able to provide care for their clients when they need it. Their commitment to organize and move ahead with the development of their palliative care team is also indicative of their vision for improving palliative care service delivery in their community.

In the Six Nations LTC/HCC focus group, they suggested who they thought should be included in a palliative care team. Their vision of a Six Nations palliative care team would include: the Six Nations LTC/HCC team, the Brant CCAC, CP/FNN, physicians, the family health team, the local pharmacy, Six Nations social workers, and the local funeral director.

In order for a physician to be a part of the palliative care team at Six Nations, the political will must be present at the federal funding level, but also at the Six Nations Health Services level as they are in a position to allocate physician hours to a palliative care team.

Six Nations LTC/HCC reported that there is a lack of recognition by Health Canada that they provide palliative care services within their overall system of care. Because there are no dedicated resources to provide palliative care services, this limits the amount that they can do, despite identifying palliative care clients as a priority for the organization. This group has repeatedly applied for funding for palliative care services, but the request has not been approved to date. Recognition and financial support of these services by Health Canada's First Nations and Inuit Home & Community Care program would strengthen their ability to provide these much needed services.

Study Strengths and Limitations

The main strengths of this study are the actions to date that appeared to result from this research taking place, even before finalizing the thesis project. The interviews with Elders and family caregivers identified priorities in care from their perspective, and the focus groups provided opportunities for dialogue amongst the care providers. Those meetings also, it appears, have facilitated improved communication among the three agencies. In addition, the five-year CIHR intervention grant awarded to Dr. Mary Lou Kelley and Dr. Kevin Brazil, likely would not have included Six Nations as a study community if my study had not taken place. I anticipate the community will benefit directly from taking part in the CIHR research because the community will have a Community Facilitator employed for five years who will work in partnership with Six Nations LTC/HCC and the research team to develop a community-based palliative care team.

Another strength of the study is the methodological approach used in the project. The participatory approach with a goal to increasing capacity for palliative care research in the community was well received by the community organizations involved in the research, as well as by the CCAC, as evidenced by their involvement in the focus groups, and also in their continuing participation in activities related to the 5-year Intervention research grant. The intervention grant also utilizes a participatory approach.

A limitation of this study is that it may be limited in the degree to which the findings may be transferable to other communities. Lincoln and Guba (1985) suggest that in qualitative inquiry, the transferability (or generalizability) of a study cannot be known by the investigator, but that enough contextual detail be provided in their study so that a reader may determine whether the findings are applicable to a new situation. The introduction to this thesis includes a description of the community and the system of palliative care delivery at Six Nations, which provides the reader the context of this study.

The system of palliative care delivery at Six Nations is unique and as such, some of the findings may not be applicable in other contexts. However, the findings from the Elder and family caregiver interviews may have relevance to other communities.

Future Avenues of Research

There are many opportunities for policy research in the area of Aboriginal Palliative Care. The issue of insufficient case management concerning Aboriginal patients that are deemed palliative and are discharged from hospital is an important area

of research, both at the provincial and federal levels, as has been proposed previously (Hanson and Associates, NAHO).

Another area that warrants attention is the issue of CCAC and its ability to provide services on reserves in Ontario, particularly when it is geographically possible to do so. It may be that the Local Health Integration Networks (LHINs) or Hospice Palliative Care Networks have a role in facilitating communication between CCACs and First Nations (FNs) within each LHIN area. The Ontario Ministry of Health and Long-Term Care may have a role in facilitating the development of policy at the LHIN level to provide services to communities within their LHIN regions.

The jurisdictional gap between the provincial and federal government with respect to health care funding is a serious issue and merits an examination of policy at both the federal and provincial level. The development of clear and actionable policies on the delivery of services to reserves is needed to create equitable access to care for First Nations people in Canada. This includes ensuring that adequate funds are available to provide those services.

Conclusions

My stated aim in conducting this project was to determine how palliative care services to the members of Six Nations could be improved. To some degree, I believe I have met this aim. In the focus groups, relationship/rapport issues were identified as a challenge, and it appeared that the focus groups provided an opportunity for communication between the organizations to improve. Identification of within-program

challenges – and ways to address these challenges - may provide opportunities for each organization to improve how palliative care services are delivered at Six Nations. For instance, if the CCAC were to implement a practice of dedicating one day a week to Six Nations clients (as discussed in the focus group), it is possible that there will be a lower likelihood of "bad deaths" taking place.

Identification of broader system factors that influence care may also provide benefit to palliative patients. With respect to the example discussed in one of the focus groups – a patient being discharged from hospital without proper supports in place (i.e., family physician) – a dialogue with hospitals on this issue could possibly prevent such instances in future. The CCAC may be in the best position to initiate this dialogue.

The five-year intervention grant will continue to build upon the accomplishments of this project and is expected to further strengthen the system of palliative care delivery at Six Nations, as well as in other First Nations in the project.

Additionally, the findings from this research will contribute to the literature on Aboriginal palliative care, specifically, on cultural competence in care, priorities in care from community perspectives, and ways in engaging Aboriginal communities in research.

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APPENDIX A

SIX NATIONS COUNCIL

October 17, 2008

Valerie O'Brien
3 Briar Lane
Dundas, Ontario
L9H 6E8

Dear: Valerie

The Six Nations Council Ethics Committee met on October 17, 2008 and reviewed your "Person-Centered Palliative Care-A First Nations Perspective" ethics application.

This will confirm that approval has been granted from the Six Nations Council Ethics Committee for you to conduct your research as requesting in your proposal, here at Six Nations with a reminder that you are to clarify how much control those involved have over the research, are they able to review only or able to review and make changes in terms of accuracy of the information.

The Committee reserves the right to request your attendance at upcoming meetings to provide written and/or verbal progress reports. Should this be a requirement, you will be provided notice in writing. **The Committee looks forward to receiving a final report upon completion of your research and is requesting that you send two copies of your final report.**

Should you have any questions or concerns, please do not hesitate to contact me by phone at (519)-445-2201 ext. 231 or by email at tlongboat@sixnations.ca .

SIX NATIONS COUNCIL

Carol M. Hill
Council Secretary

Valerie O'Brien

From:	Mirabella, Melina (Carmela) <mirabem@mcmaster.ca>
Sent:	January-21-09 1:32 PM
To:	Valerie O'Brien
Cc:	Brazil, Kevin (brazilk)
Subject:	APPROVAL LETTER

Dear Valerie,

PROJECT NUMBER: 08-612-S

PROJECT TITLE: Person-Centred Palliative Care: A First Nations Perspective

STUDENT RESEARCHER: Valerie O'Brien

SUPERVISOR: Dr. Kevin Brazil

This will acknowledge receipt of your application dated October 27, 2008 regarding the above named project.

We wish to advise you that your research project has been given ***final*** approval by the HHS/McMaster University Research Ethics Board. The submission was found to meet the minimal risk criteria and to be acceptable on ethical grounds.

We are pleased to issue final approval for the above-named student project for a period of 12 months from approval date, December 3, 2008. Continuation beyond that date will require further review and renewal of REB approval. A request for an extension of the project beyond one year must be submitted in writing to the REB along with an annual report.

Any changes or amendments to the protocol/project, or consent form must be approved by the Research Ethics Board.

All recruitment, and consent materials (including posters and other advertisements) must bear the REB stamp. If there are any changes to these documents they must be sent for approval.

We wish to advise that the Research Ethics Board operates in compliance with ICH Good Clinical Practice Guidelines and the Tri-Council Policy Statement.

Marie Townsend

Melina (Carmela) Mirabella
Administrative Assistant
Health Research Services
FHS Student Research Ethics Committee
McMaster University
1200 Main Street West, HSC-1B7
Hamilton, ON L8N 3Z5
Canada
905-525-9140, x 22258, FAX: 905-523-6061

APPENDIX B

RECRUITMENT MATERIAL

LETTER TO POTENTIAL CAREGIVER INTERVIEWEES

Dear_____:

RE: Invitation to participate in research study

I am writing to let you know that a research study assessing palliative care services at Six Nations is currently taking place.

We are currently seeking the input of people who are familiar with the day-to-day experiences of a family member or friend of a person who has received palliative care services at Six Nations.

The aim of this research is to improve palliative care services at Six Nations, though we cannot guarantee that this research will result in any changes in services offered as there are many factors that influence services that are available, but efforts will be made to follow up with any recommendations that come out of the research.
If you are interested in sharing your story, please contact me at 519-445-1328. If you feel that it is a difficult experience to talk about, please understand that we would not want to cause you any discomfort, and there is absolutely no obligation for you to participate. This is strictly a volunteer project.

Thank you for your consideration.

Manager/Case Manager
Home & Community Care Program

*This letter might come from a case manager at the Home & Community Care Program who worked directly with the family during the period of care.

APPENDIX C

Interview Guide

(Introduction)

You've signed the informed consent form, which means that you understand the goals of the study and the interview process. Remember, you have the right to stop the interview at any time, not answer certain questions, reschedule the interview if you feel uncomfortable at any point, or even withdraw from the study without any consequences to you. Are you ready to begin?

(The Palliative care experience)

1. I'd like you to think back to those experiences you are familiar with about someone who was seriously ill and received home care. I'd like to discuss that with you.

    a. What do you remember about the care they received? (Probe:What stands out for you?)

    b. How did the home care situation come about?

    c. Can you tell me who was involved in the care?

        i. What things did the care providers do that mattered the most?

        ii. What was least helpful?

        iii. How long was the care provided?

    d. Did _____ die at home? Can you tell me about that?

    Thank you. I appreciate your answers. Now I'd like to ask you about what you feel are important things that have to be considered when providing care to someone who is seriously ill and receiving care at home at Six Nations.

(Perceived Priorities in Care)

2. When a person is seriously ill and is receiving care at home, what do you think are the most important things that community health care service providers should take care of for the person and their family? (Probes: Can you give me any more examples of what you think is important? Why is that important?)(as appropriate)

    a. Are there any special considerations that health care providers should be aware of when they are providing home care for Aboriginal people?

    b. What about if they are providing home care for Six Nations people in particular? (Probe: Can you tell me more about that?)

c. Now I'd like you to think about the system of home care at Six Nations. This would include things you've heard about or experienced. Could you tell me about things that you think are examples of really good care?

d. Now, thinking again about the home care system at Six Nations, what do you think could be improved?

(Ideal Care)

3. When you think of someone in the community of Six Nations receiving excellent care,

   a. What would that look like to you?

   b. Who would provide that service?

   c. Where would it happen?

Note: Text in brackets will not be read out loud.

APPENDIX D

Focus Group/Care provider interview Questions

SYSTEM LEVEL

What are the strengths in the overall system of care?

What are the challenges?

PROGRAM LEVEL

What do you think are the strengths of your program?

What are the challenges within the program (organization)?

INDIVIDUAL LEVEL

What experiences have you had in your own daily work that is an example of how things work well?

What about any experiences where things didn't happen the way you would have liked?

OVERALL (can include aspects at any level of care)

What are the challenges that you face that affect your ability to provide care?

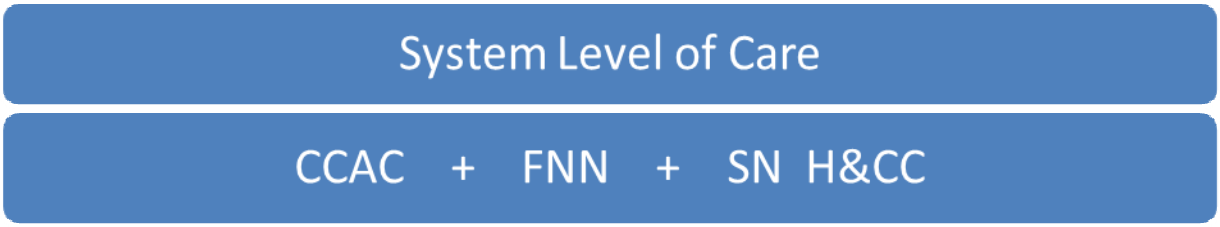
Is there anything that would enhance your ability to provide person-centred care?

What resources might help you in that aim?

APPENDIX E

Palliative Care at Six Nations

Palliative care services at Six Nations are offered within a system of care with services provided through the Brantford Community Care Access Centre (CCAC), First Nations Nursing (FNN), and the Six Nations Home and Community Care Program (SN H&CC). This can be thought of as the system of care.



Services are offered at the program level, i.e., services offered by a particular program, i.e., Six Nations Home & Community Care, or by First Nations Nursing.

Services are offered at the Individual Level, by individual people. For example, care is provided by case managers, nurses, and PSWs.

APPENDIX F

Person-Centred Palliative Care at Six Nations

A research project to assess palliative care services currently available

Information Sheet/ Consent Form

Researcher: Valerie O'Brien

Program of Study: Masters of Science, Health Research Methodology, McMaster University

Contact information: 905-973-7138
vobrien@mcmaster.ca

Supervisor's Name: Dr. Kevin Brazil, PhD, McMaster University

You are being invited to participate in a study about palliative care services that are available to residents of Six Nations.

What is palliative care? Palliative care is the special care of a person whose disease cannot be cured. Palliative care provides comfort and support to the person and family. Palliative care does not hasten or delay death. [1]
http://www.palliative.org/PC/GeneralPublic/PalliativeCare/WhatIsPC.html

The research questions that guide the research are:

How do various community members of the Six Nations of the Grand River view the current system of palliative care offered to them with regards to its ability to provide person-centred care for its community members?

What do community members/care providers recommend be done to improve the palliative care services provided to Six Nations community members?

The identified objectives of the research are to:

1. assess how various stakeholder groups within the Six Nations community define person-centred palliative care,

2. determine the degree to which services currently offered on the Six Nations reserve enables that to occur, and

3. obtain recommendations on how to improve palliative care services currently being offered to the Six Nations community.

This research study will look at the aspects of palliative care that are important to Six Nations members, and will also look at the experiences that people at Six Nations have had in the past. Once we have information on these topics, we will present the findings to people who provide palliative care to Six Nations members and ask them about how well their services match up with what people would like in terms of palliative care. We will also work with them to find out what the strengths of the program are, as well as identifying the challenges they face. The intent of the research is also to find ways to improve services that are currently available.

People who volunteer to participate in the study will be interviewed and asked questions related to care of the seriously ill. The interview will likely take between 30 – 60 minutes.

The findings from this study may be presented at conferences or published in a journal so that others may learn from it. A report will also be prepared for the community that will be presented in a community environment after the research is complete. This research project is the basis for the researcher's master's thesis project.

Potential Harms

It is not likely that participants will be harmed through participation in this study, though discussing these sensitive issues may cause some sadness. Participants are urged not to participate in this study if they feel they will suffer any kind of harm, including emotional distress. Should a participant decide to participate and following the interview feel they need emotional support, a Six Nations social worker will be available to provide that support for a period after the interview.

Potential Benefits

This research project has the potential to improve the level of palliative care services in the community of Six Nations through the development of recommendations that will support the provision of person-centred palliative care for Six Nations members.

Confidentiality

The information that will be collected will be kept in a safe manner so that the confidentiality of all participants is protected. Data presented will be presented in a "group" manner, so that individual contributions from participants will not allow the participant to be identified. Individuals will not be identified in any publication or conference presentation. All information collected by the researcher will only be viewed by the researcher, and her supervisor, if requested, and will remain strictly confidential. The audiotape of the interviews will be erased once the researcher types out the content of the tape. You will have the opportunity to review what the researcher has written down from the audiotape and to correct or clarify anything that has been recorded. The written

data will be kept for 10 years as recommended by the McMaster University Research Ethics Board. It will be stored in a locked file cabinet.

Your rights

If you take part in this study, you have the right to refuse to answer any particular question, and also to withdraw from the study at any time. You have the right to ask any questions about the study. You also have the right to be given a summary of the findings from the study when it is concluded.

Participation

Participation in research must be voluntary. If you choose to not participate, you will not suffer any consequences whatsoever. If you choose to participate and later decide to change your mind, you can say no and stop the research at any time. Again, there will not be any negative consequences for you if you choose to withdraw from the research. Any documents related to your participation will be destroyed should you choose to not participate in the research after the interview has taken place.
If you have any questions regarding your rights as a research participant, you may contact the office of the Chair of the Hamilton Health Sciences/Faculty of Health Sciences Research Ethics board at 905-521-2100 ext. 42013.

CONSENT

I have read the information presented in the 3-page information sheet/consent form about a study about palliative care services at Six Nations being conducted by Valerie O'Brien, of McMaster University. I have had the opportunity to ask questions about my involvement in this study, and to receive any additional details I wanted to know about the study. I understand that I may withdraw from the study at any time, if I choose to do so, and I agree to participate in this study. I have been given a copy of this form.

_____

Name of Participant Date

_____

Researcher Date