

Mount Saint Vincent University

Department of Family Studies and Gerontology

**Palliative care in long-term care:
A multi-methods approach to assessing quality**

by

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**Palliative Care in Long-Term Care:
A Multi-Methods Approach to Assessing Quality**

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Abstract

Palliative Care in Long-Term Care: A Multi-Methods Approach to Assessing Quality

Long-term care facilities provide care for chronic illness, usually until death yet little research is directed at the provision of palliative care in these settings. With the population in Canada aging an increasing number of people will require long-term care services including hospice palliative care. There is a need for empirical knowledge that will contribute to policy development, implementation, and evaluation in this increasingly important area of health care service delivery. The main objective of this research was to define high quality hospice palliative care service delivery through the exploration of approaches taken to provide palliative care at Veterans Affairs Canada (VAC) facilities across Canada.

This study was guided by the Canadian Hospice Palliative Care Association's (CHPCA) (2002) *A Model to Guide Hospice Palliative Care*. Five facilities across Canada were selected for their high quality of palliative care programming as defined by representatives from VAC. Data collection included written policies submitted by participating facilities, interviews with two key informants from each facility, and field observations of three front-line care workers at one facility. Analysis involved coding of data using QSR NUD*IST software. A normative policy analysis of the coded data was conducted using the CHPCA model as a policy framework.

Results indicated that the components of the studied policies at each facility were similar and were, for the most part, in keeping with the domains of care included in the CHPCA model. Each of the programs were well resourced. Approaches to program implementation were individualized based on facility needs. Barriers to care included

pain assessment of residents with dementia, interpersonal conflict, and human resource deficiencies during expected deaths and health crises. A lack of recognition of the emotional toll paid by front-line workers was also determined to be a barrier to quality care. Enhancers included a wide range of service availability, knowledgeable front-line care workers, and a high capacity for maintaining continuity of care through effective communication, interpersonal relations, and team approach to care.

Findings suggest that the principles of palliative care were evident in the programs provided by participating facilities and their experiences may enable other facilities to introduce palliative care. The hospice palliative care services available at the participating facilities provided a quality of life for residents that effectively demonstrated a need for improved funding and services in this area of care at long-term care facilities across Canada. Although participating facilities were well funded, further resources needed to be directed towards providing emotional support and bereavement care for both families and care providers.

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Introduction

Problem Statement

The population in Canada is aging at a steady rate. Between 1991 and 2001 the number of people in Canada aged 80 and older increased by 40% (Cranswick, 2003). A large proportion of this population requires elevated levels of health care service (Cranswick, 2003), such as palliative care. Palliative care is a service that is of concern to the aging population and has received increased attention in recent years. As the population ages, more people will face the prospect of end-of-life decisions as the risk for chronic and terminal illnesses increase. Hospice palliative care is a treatment approach that may improve quality of life for many aging individuals who face such an illness.

In particular, residents of long-term care facilities in Canada and their families are faced daily with the prospect of making end-of-life decisions. Although the body of research relevant to hospice palliative care service delivery in this care setting has begun to grow, significant knowledge gaps still exist. Facility staff who are tasked with facilitating care decision-making, planning, and delivery need the support of empirical knowledge to guide their daily care roles. The main objective of this research was to define and assess quality in hospice palliative care service delivery in the long-term care setting through the analysis of hospice palliative care policies and programs at facilities contracted by Veterans Affairs Canada (VAC).

Background

Until the early 20th century the most prevalent causes of death in North America stemmed from infectious diseases and accidents (Berger, 2001). However, now with the population aging, more people will face chronic and/or terminal illnesses (Chrystal-Frances, 2003). The main goal of palliative care research is to find ways to improve the

quality of care and in turn the quality of life, of residents who face these circumstances and their families (Richards, Corner, & Clark, 1998).

Currently, the home is considered the preferred place of care for most aging Canadians. Of the urban senior population 93% are living and/or cared for at home (Turcotte & Schellenberg, 2006). According to the 2001 Canada Census fewer than 10% of senior women and 5% of senior men are residing in health care institutions (Cranswick, 2002). In recent years there has been a shift away from institutional care towards the home. Nevertheless, long-term care is still a required health care service for a large number of Canadians. In 2001, two percent of individuals aged 65-74 years resided in institutions. This proportion increased to 32% for Canadians 85 years of age or older (Turcotte & Schellenberg, 2006). According to a Statistics Canada report (Turcotte & Schellenberg, 2006), women in this age group were significantly more likely to be in receipt of institutional care. This is a segment of the population that cannot be ignored simply because their numbers are small relative to the rest of the Canadian population.

An assessment of hospice clients in nursing homes in the US revealed that the average age of residents at admission was 76.4 years. Fewer than 6% were below 50 years of age (Buchanan, Choi, Wang, & Huang, 2002). This population is distinctly elderly and their health care needs are ever evolving, requiring constant evaluation. Between 2000 and 2002, death rates from cancer in Canada stayed the same or increased in all senior age groups, while deaths from all causes declined (Turcotte & Shellenberg, 2006). According to Buchanan et al., (2002), the most common diseases for recently admitted nursing home hospice residents in the US are cancer (57%), hypertension (35%), congestive heart failure (21%), emphysema/chronic obstructive pulmonary

disease (20%), and depression (18%). This change in disease distribution indicates a real need for palliative care services aimed specifically at the elderly population.

The wide range of diseases affecting the elderly in long-term care indicates that the aging process can be accompanied by a diversity of needs. The Canadian government faces the prospect of developing social programs to meet many competing needs with a scarcity of resources. Relevant research needs to be developed that may help to inform and guide policy makers as they make decisions that will affect seniors who rely on health and social services. Palliative care, in particular, is a care need that is often overlooked by researchers and policy makers alike.

Death is an inevitable part of nursing home culture (Forbes, Bern-Klug, & Gessert, 2000). Nursing homes provide care for long-term illnesses, usually until death (Froggatt, 2001), yet there is little research directed at the provision of hospice palliative care in the long-term care setting. Research in this field has begun to grow in recent years, but the vast majority of studies are being undertaken in the United States, and the US population falls under a very different health care system than the system existing in Canada. If palliative care services are to be delivered effectively in Canada, empirical evidence derived from Canadian populations must support policy development, implementation, and evaluation. This research provides information to decision makers that will be valuable in the development of palliative care policy.

Research Questions

Keeping the assessment of quality palliative care programming in mind as the main objective, this study answered the two following questions. First, what are the components of a quality palliative program in the long-term care setting? Second, what

are the barriers and enhancers to developing a best practice palliative care program in the long-term care setting?

The overarching framework used to answer the above questions was the Canadian Hospice Palliative Care Association's (CHPCA) (2002) *A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice*. This model includes "frameworks, principles and norms of practice to guide [resident]/family care, and organizational development and function" (Ferris et al., p. 5). Criteria used for analysis was guided by the CHPCA model and includes its foundational concepts, guiding principles, and norms of practice. The norms of practice were developed by the CHPCA in the areas of assessment, information sharing, decision making, care planning, care delivery, and confirmation. The foundational concepts and guiding principles are further defined in subsequent sections.

Defining Hospice Palliative Care

High quality end-of-life care as an insured service is a growing concern for many Canadians (National Advisory Council on Aging, 1999). This care has been referred to in the past as *hospice care* or *palliative care*. The Canadian Hospice Palliative Care Association has combined these terms (Ferris et al., 2002) and defines *hospice palliative care* as service providing:

physical, psychological, social, spiritual and practical support to people living with life threatening illness and to their loved ones. Care teams include physicians, volunteers, nurses, spiritual counselors, friends and family. It can be provided, at home, in hospitals, nursing homes or free-standing hospice facilities (p.17).

The primary goals of palliative care differ from those in other areas of health care.

Whereas the main goal for a resident in the early stages of cancer treatment may be the prolongation of life, comfort and supportive care may be more important for those in the advanced stages of cancer (Richards et al., 1998).

Although hospice palliative care is an approach to care that has developed for those facing a terminal illness, it may be also be beneficial for those approaching the end-of-life due to any cause, such as a chronic illness or an acute event, and may be offered at any point in the disease progression (Zerzan, Stearns, & Hanson, 2000). This method of providing palliative care services may be referred to as end-of-life care or a palliative care approach. Palliative care is now accepted as a central component of any good clinical practice, regardless of the care setting (Payne, Smith, & Dean, 1999). It is an approach that accepts the improvement of quality of life over curative or life-prolonging treatments for those facing end-of-life decisions (Chrystal-Frances, 2003).

Conceptual Framework: The Canadian Hospice Palliative Care Association Model

The Canadian Hospice Palliative Care Association published the document *A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice* in March of 2002. This model is the end result of a ten-year, nationally based, consensus-building process led by the Standards Committee of the Canadian Hospice Palliative Care Association and was developed in consultation with experts in the field. It is based on patient and family needs. The rationale behind developing this standardized approach to hospice palliative care is included in the document and includes an assurance that “all [care providers] are knowledgeable and skilled, and have the support they need to fulfill their role” and the provision of a tool to help “reveal any gaps in care and

encourage organizations to expand their services or develop partnerships with other healthcare providers to fill these gaps” (Ferris et al., 2002, p. 1).

The CHPCA proposed several uses for its model. There are three specified functions that are relevant to this study. First the model may be used to “guide patient and family care provided by both primary and expert [care providers]” and, second to “guide the development and function of hospice palliative care organizations” (Ferris et al., 2002, p. 2). Third and most relevant to this study, the model may also be used to “guide research in palliative care” (Ferris et al., 2002, p. 2). During this project, hospice palliative care programs were selected for high quality resident and family care and were evaluated to understand how *quality hospice palliative care* is defined in the long-term care setting. The CHPCA guidelines are hoped to provide further guidance to long-term care facilities across Canada in the development and implementation of palliative care programs. The CHPCA model provides specific criteria for the analysis of data collected and the assessment of quality programming and service delivery.

The provision of care to an individual at the end of his or her life is an incredibly important yet difficult task. If the individual has accepted a terminal diagnosis, the most important goal of care is the improvement of quality of life in the final phase of life. Palliative care services must be developed keeping this goal in mind. The CHPCA model proposes several guiding principles and foundational concepts that must be taken into consideration when developing and delivering palliative care services. The Guiding Principles as defined by the CHPCA (Ferris et al., 2002) are as follows:

Resident/Family Focused- Residents and family are treated as a unit. Care provided respects individual needs as dictated by personal, cultural, and religious

values and beliefs.

High Quality- Ethical principles and standards guide all hospice palliative care practice. Palliative care service delivery is based upon nationally-accepted norms of practice, best available evidence, and standards of professional conduct for each discipline.

Safe and Effective- All hospice palliative care practices ensure privacy and are conducted without coercion, discrimination, or harassment. Service delivery guidelines ensure continuity and accountability. All activities are conducted in a manner that aims to minimize unnecessary repetition and complies with laws, regulations, and policies in effect within the jurisdiction.

Accessible- All residents and families have access to hospice palliative care services in a timely manner.

Adequately Resourced- Resources available are sufficient to sustain all hospice palliative care activities.

Collaborative- Representatives from long-term care facilities collaborate with available organizations to ensure hospice palliative care needs are assessed and addressed.

Knowledge-Based- Residents, families, and care providers are provided with ongoing education in hospice palliative care.

Advocacy-Based- Representatives involved in long-term care hospice palliative care programs interact regularly with individuals and organization key to the advancement of hospice palliative care policy, as well as the public, to increase awareness about and improve access to hospice palliative care activities.

Research-Based- Research in the area of hospice palliative care is crucial to its advancement. When possible, care provided is based on best available evidence.

The Foundational Concepts outlined in the CHPCA model are summarized as follows

(Ferris et al., 2002, pp. 21-23):

Effective Communication- Effective communication is fundamental to both the process of providing care and the function of a hospice palliative care program. To be effective, hospice palliative care [providers] must share a common language, use a standard protocol to communicate, collect data that documents the resident's and family's status, and educate residents, families, and [care providers].

Effective Group Function- All activities related to hospice palliative care revolve around multiple groups that have specific purposes and tasks. Each group is subject to all of the dynamics of group formation and function. To be effective, all groups need skilled leadership that facilitates their activities and promotes effective group dynamics. Groups in hospice palliative care include the resident and family, the careteam, regional team of [care providers], and the organization's management team, committees and workgroups.

Ability to Facilitate Change- Hospice palliative care aims to help [resident] and families manage the challenges and opportunities they face during their changing illness and bereavement experiences. To fulfill that goal [care providers] must be skilled at maximizing openness and adaptability in the attitudes, knowledge, skills and behaviours of everyone involved in the therapeutic relationship. They must also have specific skills to assist [residents] and families through the transitions they experience during illness and bereavement. Similarly, all aspects of organizational development and function, education, research and advocacy are also based on the effective application of change strategies.

In addition to the Guiding Principles and Foundational Concepts, the model suggests components necessary to comprise a comprehensive palliative care program.

These include disease management, physical care, psychological care, social care, spiritual care, practical care (activities of daily living, infrastructure), end-of-life care/death management, and loss/grief (Ferris et al., 2002).

A possible criticism of the CHPCA model is that much of the empirical

knowledge used in its development stems from research conducted in acute care and home care settings. Even so, it is the best available model for the use in the development of palliative care service delivery in the long-term care setting. The CHPCA provides a model to guide patient and family care and to guide organizational development and function. Included in this model are principles and norms of practice to guide: (a) assessment, (b) information-sharing, (c) decision-making, (d) care planning, (e) care delivery, and (f) confirmation. Each of these components has applications in each of the three care settings; however, the relative importance and implementation of each component may be very different. For example, although care delivery will most often occur on a 24-hour basis in acute care, it may be limited to a certain number of hours in long-term care. Physician care may be readily available in the acute care setting, whereas long-term care facilities may be more reliant other health care workers such as nurses and continuing care assistants.

With regards to implementation of hospice palliative care policy, Ferris et al., (2002) states,

There are two main aspects of the model to guide hospice palliative care: the delivery of [resident] and family care, and the development and function of organization... The two are inextricably linked. They are guided by the same definitions, values, principles, and foundational concepts (p.54).

For the purposes of demonstrating these two aspects of care, the CHPCA model includes a *Square of Care* and a *Square of Organization* (Ferris et al., 2002). The Square of Care provides an explanation of how principles and norms of care, namely those listed in the previous paragraph, are used to guide resident care. The Square of Organization illustrates how resources are combined with principle functions, including governance, administration, operations, quality management, and marketing to develop and facilitate

organization. An integrated *Square of Care and Organization* depicts the organization supporting all clinical activities with the resident and family central to both the Square of Care and the Square of Organization.

With respect to the resident specifically, the model may represent a different initial level care as compared to individuals in other care settings. In the acute care and home care settings palliative care may be introduced as an option around the time of diagnosis of a terminal disease. Palliative care treatments may be gradually introduced, as curative treatments become less and less the main focus of care. When a resident is initially placed in a long-term care facility, the care team must assess his or her care needs. In many cases the resident may already be in a position to benefit from a palliative care approach, but may not be ready to accept this type of treatment. He or she may suffer from chronic conditions or terminal illness that have a longer disease trajectory. Residents or family may desire curative treatments even though cure is not possible and these treatments may decrease quality of life. Conversely, a resident may have been receiving palliative care treatments while awaiting nursing home placement. The same care plan may not be an option upon placement at a long-term care facility due to staffing or funding availability.

Through the course of this research the CHPCA model was used to guide analysis of data collected and to determine how hospice palliative care within the long-term care setting fit within the model. Defining quality hospice palliative care in the long-term care setting helped gain an understanding of how the CHPCA model can be applied in this unique care setting.

Review of the Literature

At present, hospice palliative care is a relatively new and emerging field of research. Researchers have only begun to develop an accessible body of empirical knowledge relevant to the field. A review of current literature pertaining to hospice palliative care service delivery in the long-term care setting was conducted resulting in the emergence of seven broad trends relevant to the quality of these services. These trends are effective pain and symptom management, resident-focused care, communication, knowledge, resource allocation, family support and bereavement care, and staff support. These trends are summarized in the following sections.

Effective Pain and Symptom Management

The primary goal of hospice palliative care is to maximize the quality of life experienced by individuals faced with a life threatening illness (Ferris et al., 2002). To this end, care providers are tasked with limiting pain and other discomforting symptoms to the greatest extent possible. In hospice palliative care, care providers aim to relieve not only physical pain, but the total pain experienced by the resident as well. *Total pain* is described by Winn and Dentino (2004a) to be comprised of four components. These components are physical pain, emotional pain (anxiety, depression, anger), social pain (interpersonal problems, loneliness, strained family relationships), and spiritual pain (non-acceptance of the terminality of life, hopelessness, search for meaning). It is particularly important to treat all pain in residents of long-term care facilities, because under-treatment of total pain can lead to decreased levels of function and socialization (Winn and Dentino, 2004a). The result may be a lowered quality of life. However, the majority of evidence reviewed centred on the experience of physical pain and discomfort

and neglects the other three components of total pain. Several recent studies focused primarily on the incidence and prevalence of physical pain as well as the importance and quality of treating physical pain in the long-term care population (Baer & Hanson, 2003; Bernabei et al., 1998; Hall, Schroder, & Weaver, 2002).

Families of long-term care residents receiving hospice palliative care treatment reported that they considered pain management to be a treatment priority followed by comfort care (Vohra, Brazil, Hanna, & Abelson, 2004). From the perspective of some nursing home staff, treatment of pain and other discomforting symptoms may be under control (Brandt, Deliens, van der Steen, Ooms, Ribbe, & van der Wal., 2005), but several studies in the United States looking at the prevalence and severity of pain in the elderly residing in long-term care facilities reported that pain is both under-reported and under-treated (Bernabei et al., 1998; Johnson, Teno, Bourbonniere, & Mor, 2005; Winn & Dentino, 2004a).

Several studies reviewed detailed the reported experience of pain in residents of long-term care. In a survey of 292 family member of deceased nursing home residents, 33% rated the pain that their loved-one experienced on a daily basis as severe, 37% rated it as moderate and 20% rated it as mild. Twenty-three percent said that their loved-one experienced pain all the time (Baer & Hanson, 2000). In a review of 1995 Minimum Data Set (MDS) data for 13,625 nursing home residents aged 65-years or older with a diagnosis of cancer the results were similar. This study reported that 38% of those individuals aged 65-74 experienced pain on a daily basis, as did 29% of individuals aged 75-84 years and 24% of those aged 85 years or older (Bernabei et al., 1998). A review of 1999 MDS data concluded that 56.9% of US cancer patients residing in nursing homes

were in pain at admission and of these 51.3% experienced persistent, severe pain (Johnson et al., 2005). From a Canadian perspective, a chart audit conducted in five nursing homes revealed that 62% of residents reviewed experienced dyspnea and 44% experienced pain in the last forty-eight hours of life. Treatment of these and other symptoms could be complicated as 53% of patients experienced three or more discomforting symptoms (Hall et al., 2002). The incidence and prevalence of physical pain and its assessment needs to be further studied to gain an understanding of the extent of this issue in Canada.

An issue that may complicate the treatment of pain and other discomforting symptoms in the long-term care population is a possible correlation between age and the under-reporting of pain. Berger (2001) states that, “older people are one of the most under-treated populations with regard to pain and should be considered a group at risk for mismanagement of pain and symptoms (p. 49). Additionally, Bernabei et al., (1998) found that although the prevalence of reported daily pain declined with age the mean number of co-existing medical condition also increased with age. The higher mean number of co-existing conditions could indicate that pain is being under-reported in older cohorts leading to under-treatment.

According to the literature, there are several reasons why pain may go under-reported in the elderly. One challenge is that, “residents may be reluctant to report pain, often viewing it to be an expected concomitant of aging” (Bernabei et al., 1998, p. 1880). There may also be a tendency for this cohort to be more “stoic” than other younger cohorts. In some cases, the ways in which pain is communicated may be missed by those assessing it. For example, pain may be described instead as burning or aching (Winn &

Dentino, 2004a). In addition, those suffering from dementing illness may have difficulty articulating the pain they are experiencing. These individuals may communicate pain through other means, such as facial grimacing, moaning, or agitation (Panke & Volicer, 2002).

Resident-Focused Care

Although there are some unique challenges to providing effective pain and symptom management in the long-term care setting, the goal to eliminate pain and other discomforting symptoms is the same across all care settings. A key difference between residents receiving palliative care in a nursing home and those in a hospital setting is that the institution is considered to be the resident's home. In addition, the majority of long-term care residents were elderly and often experienced several co-existing medical conditions (Bernabei et al., 1998), making the delivery of palliative care in this setting unique as compared to other care settings where palliative care may be focused on managing one medical condition such as cancer. Goals for treatment needed to be very individual as the combination of medical conditions frequently varied greatly. To be effectively implemented in the long-term care setting, it was suggested that hospice palliative care should be extended to treat a variety of conditions other than cancer, including dementia (Sebag-Lanoë, Lefebvre-Chaprio, Fetenau, & Trivalle, 2003). The goal to effectively manage "total pain" requires that all care be *resident-focused*.

It is a fundamental premise of hospice palliative care that that when a disease can no longer be effectively treated, care is geared towards maximizing quality of life and ensuring that death occurs in a manner consistent with the values and wishes of the resident (Berger, 2001). Nursing home staff were found to support this view. One

Canadian study concluded that nursing home staff believed that quality care meant responding to the residents' needs (Brazil, McAiney, Caron- O'Brien, O'Krafka, & Sturdy-Smith, 2004). Resident needs included physical care, fostering respect and dignity, recognition of cultural and spiritual needs, and the provision of social support (Brazil et al., 2004). When residents cannot make decisions for themselves, care must still concentrate on responding to their individual needs. Even when they became incapable of expressing their needs and making their own decisions, family members valued quality of life, autonomy, and preservation of dignity (Forbes et al., 2000; Vohra et al., 2004).

An Australian study concluded that resident-focused care can sometimes be achieved in very simple ways (Parker, Grbich, Brown, Maddocks, Willis, & Roe, 2005). For example, residents interviewed for this study expressed how important it was to be able to have their own belongings in their room. Some residents responded well to individual and groups activities offered by recreation therapists. Alternatively, staff at the participating facilities acted to decrease feelings of isolation in other residents who were less comfortable in social settings by sitting and reading to them.

Communication

Resident-focused care requires that staff gain a complete understanding of each resident's individual needs and wishes. For this to happen there must be open lines of communication between all groups involved to ensure the resident's individual needs are understood and met (Ferris et al., 2002). It was found that communicating accurate information to the family and resident assisted them in making difficult decisions about end-of-life care (Forbes et al., 2000). The care team needed to be able to educate families

and residents about health status, prognosis, and the risks and benefits of available treatment options. This communication also allowed residents and their families to prepare for the eventuality of death. Lack of knowledge about disease processes was determined to be a barrier to appropriate decision-making regarding care (Bern-Klug, Gessert, Crenner, Buenaver, & Skirchak, 2004).

Field observations conducted in a long-term care hospice palliative care unit revealed that when hospice palliative care was working well, the resident and family were an integral part of care planning and delivery. Open communication was encouraged on a daily basis (Kayser-Jones, Chan, & Kris, 2005). Communication between residents and families and the care team began with advanced care planning. Advanced care planning differed from advanced directives in that it was a dynamic process. It began with the resident and family expressing their desires for treatment when the resident was first admitted to the facility. At various intervals of time the plan was revisited and the resident had the option of changing it if he or she so desired. The plan was reviewed if there was a significant change in health status requiring a change in the care plan (Forbes et al., 2000).

Advanced care planning was especially important when the resident suffered from a dementia-type illness such as Alzheimer's Disease. Participating in care planning in the early stages of the disease allowed the resident to express his or her wishes for treatment while they were still cognitively able. This also helped to prevent the family from being as burdened by such decisions as the disease progressed (Forbes et al., 2000).

Results of previous studies indicate that lack of communication could make decision-making very difficult (Bern-Klug et al., 2004; Vohra et al, 2004; Wetle, Shield,

Teno, Miller, & Welch, 2005). Families sometimes became distressed when they were not properly informed about their loved-one's health status. Research revealed that communication between staff and families may be an existing challenge in treating dying residents in the long-term care setting. Families surveyed about end-of-life care services indicated overall dissatisfaction with the level of information received about the resident's health status at the end-of life (Vohra et al., 2004). When faced with end-of-life care decisions the experience of many family members was that, "health care workers only rarely initiated conversation about end-of-life care preferences and that lack of clarity about the resident's prognosis sometimes led to urgent and difficult decisions" (Wetle et al., 2005, p. 646).

Family members became distressed if they did not understand why the care team was recommending against certain approaches to care, such as tube-feeding or antibiotics. In addition, they became confused by the complexity of care options available if the care options were not properly explained (Pekmarzaris et al., 2004). Moreover, a lack of understanding of available care options could lead to inappropriate decisions being made for the resident. Although families did not want to see a loved-one suffer, without proper guidance families sometimes felt compelled to treat the treatable, even when it prolonged dying or caused undue suffering (Forbes et al., 2000). Regular education sessions for families on a variety of topics including grieving, the dying process, and relaxation may help families to make informed decisions, plan, and cope (Panke & Volicer, 2002)

Communication between team members has also been identified as very important. It was essential that the team was able to come to a consensus understanding

of the resident's health status and the approach to care (Bern-Klug, Gessert, Crenner, Buenaver, & Skirchak, 2004). Team meetings were a common method of allowing the team to come together for information sharing, consultation, and interdisciplinary coordination (Sebag-Lanoë et al., 2003). Lack of communication between professionals sometimes led to gaps in care and redundancy in care roles (Brazil et al., 2004).

One barrier to effective communication between care team members was the low staffing level of nurses in long-term care facilities. When nurses were stretched thin with their time attending to many residents, the focus of care became treating what was in front of them rather than communicating with one another. In addition, physicians were often challenged in the limited amount of time they had available to spend at the facility. The result was that onsite nursing staff had limited contact with physicians providing inadequate time for effective communication (Brazil et al., 2004).

Knowledge

The delivery of effective hospice palliative care requires that all members of the care team be skilled and knowledgeable in this speciality. However, service providers indicated that ongoing training and education in palliative care was a need much less likely to be met than other needs such as team communication, access to specialist advice, and manageable caseloads (Kelley, Sellick, & Linkewich, 2003). Service providers, "stressed the importance of education to ensure that practitioners, including both family physicians and LTC staff, have the relevant attitudes, knowledge, and skills to care for dying residents" (Brazil et al., 2004, 90). In particular, education in pain management and symptom management was a common concern for care providers (Brazil et al., 2004).

Effective hospice palliative care also requires that those delivering care have an understanding that hospice palliative care can improve the quality of life of many residents who are not yet in the final stages of a terminal illness. Hospice palliative care has the potential to be an effective treatment approach for individuals who suffer from a wide range of illness, even if death is not expected in the short-term. For example, Alzheimer's Disease, "is characterized by a progressive and non-reversible loss of function, memory, and cognition skills" (Panke & Volicer, 2002, p. 144). Although, Alzheimer's Disease has a much longer disease trajectory than many cancers it is still considered a terminal illness and care planning should take this into account (Panke & Volicer, 2002). The same may be said about several other conditions commonly seen in nursing home residents, such as Parkinson's Disease and Chronic Obstructive Pulmonary Disease (COPD). Professionals must have the knowledge about how these and other diseases will progress and their available treatment options so they can accurately inform families.

Resources

It would be impossible to deliver effective hospice palliative care services without the appropriate resources. Financial, human, information, physical and community resources must all be sufficient to meet the individual needs of dying residents (Ferris et al., 2002). Brazil et al., (2004) found that long-term care staff perceived sufficient institutional resources to be necessary in the delivery of quality end-of-life care. In particular, participants in this study felt that adequate staffing and availability of equipment and supplies could improve the quality of care received by dying residents.

Insufficient resources are a potential barrier to effective hospice palliative care.

Brazil et al., (2004, p. 90) states, “staffing ratios were a consistent issue among focus group participants,” and that, “adequate staffing must be considered in relation to differing needs of residents, and the skills and knowledge required in providing care.” Others concluded that consistency in staff scheduling was also an issue. Unit staff needed to work with residents often enough to get to know their individual needs. Physicians noted a reliance on unit staff to communicate information about health status and pain levels, often over the phone. If unit nurses did not know the residents well, physicians received differing information between shifts resulting in inconsistent care (Bern-Klug et al., 2004).

Human resources were an even greater barrier to quality hospice palliative care in rural areas where recruitment and retention of service providers was a greater issue (Kelley et al., 2003). In these areas, direct care was less frequently provided by physicians. In addition, other professional service providers were required to work outside the job their education prepared them for. For example, a nurse may have to work as a community counsellor in order to have that community need fulfilled. Even in their trained roles, service providers were often required to be generalists as opposed to specialists. Delivering palliative care was frequently only one component of their job position leaving palliative care services spread thin. For example, in a Northwestern Ontario survey of non-physician health service providers, 93.4% reported that palliative care was one of several tasks for which they were responsible (Kelley et al., 2003).

Long-term care staff were not the only stakeholders who perceived staffing levels to be an issue. In a study of family perspectives on end-of-life care in long-term care, staffing levels were among several components of care that received low satisfaction

ratings (Vohra et al., 2004). Although some family members, “had positive experiences and many were sympathetic to the staff, they were also worried when low staffing levels seemed to prevent the proper administration of basic care” (Wetle et al., 2005, p. 646) . The level of staffing in long-term care settings was found to be a concern to many stakeholders from varying perspectives. It is an important issue that needs to be addressed if hospice palliative care services are to be effectively delivered in the long-term care setting.

A study conducted in the United States found that insufficient resources also resulted in an inability to care for the dying resident altogether (Botrell, O’Sullivan, Robbins, Mitty, & Mezey, 2001). This led to the resident being transferred to an acute care facility to ensure his or her needs were met. Although most nursing home staff in this study felt they could provide better care for their dying residents than the nursing staff available at acute care facilities, a lack of availability of technological and personnel resources at some facilities influenced decisions to transfer some residents to acute care. For example, where one or two nurses were responsible for upwards of 52 residents over a night shift it was felt that acutely ill residents requiring a great deal more care than others should be transferred to acute care. The issue here was that the decision to transfer sometimes caused distress for someone whose wish was to be cared for in place, especially at the end of life.

Although not as tangible a resource as equipment or staffing ratios, facility space and atmosphere also appeared in the literature as an important influence on the quality of care received and quality of life experienced by dying residents. Brazil et al., (2004) reported that long-term care staff participating in focus group discussions believed that

creating a home-like environment for dying residents was integral to quality end-of-life care. Privacy was a key component of this environment. Staff felt that the resident should be allowed their own room during palliation. This was also seen as important for roommates who experienced distress when living with a dying person. This distress was heightened by cramped quarters as family member spent time with the dying resident. Noise became a problem, for example, when televisions are turned up for someone who was hearing impaired or behavioral issues associated with cognitive decline included shouting or wailing (Brazil et al., 2004).

Another component of space as a resource was the institutional feel of many long-term care facilities (Brazil et al., 2004). Atmosphere influenced care through minute details. These included warm décor, keeping noise at a minimum, and having soft music playing at a background level. It was found that atmosphere demonstrated to residents that the staff cared and when it declined the result was feelings of alienation and isolation (Kayser-Jones et al., 2005).

Although space may be at a premium in many long-term care facilities accommodating families during final days of a resident's life improved the quality of end-of-life care received by the resident. This was done through staff responsiveness to families needs. In terms of space, facilities provided a family room where the family retired for respite from time to time or even stayed over night (Brazil et al., 2004).

Family Support

The CHPCA model advocates for hospice palliative care directed at care for the family and the resident as a whole. Family support during the resident's terminal illness and after his or her death is important for the following reasons:

If the family group can deal with the multiple losses and changes associated with death, and make the transition through their bereavement experience safely, the survivors will rebuild their lives successfully and reintegrate into society. If the transition is not successful, surviving family members may themselves become patients in the healthcare system, burdens on society, or ineffective employees. (Ferris et al., 2002, p. 13)

Hospice palliative care should aim to promote the physical, psychological, social, and spiritual well-being of the family and the resident. Although the family is affected by the resident's terminal illness during his or her life and after the death event, there is relatively little research that touches on family support as compared to other components of hospice palliative care.

As important as family support is, there may not be enough focus directed to this component of care in the long-term care setting. In a Canadian study, although overall families surveyed indicated they were satisfied with the quality of end-of-life care offered in each of the six facilities studied, family support received low satisfaction ratings (Vohra et al., 2004). However, a study of staff perceptions of quality end-of-life care determined that long-term care staff felt that family support was an important component of end-of-life care in this care setting. In particular, the participants included family education about the dying experience, the provision of emotional support, and facilitation of the decision-making process to be integral components of family support during end-of-life care (Brazil et al., 2004). Although family support was perceived to be important by facility staff, it received low satisfaction rating by those receiving care. It would be necessary to explore how family support is being delivered to further understand where gaps in this service exist.

Family support is needed especially when family members are required to make decisions on behalf of the resident. In a study of family members of nursing home

residents with dementia it was found that there was an overwhelming feeling of guilt and burden associated with making decisions about treatment for dying loved-ones (Forbes et al., 2000). Nursing home placement in itself was, “experienced as a violation of life-long values placed in fidelity” (Forbes et al., 2000, p.253). Family members also expressed distress over having to split themselves between nursing home visits, responsibilities to families at home, and their own personal needs. Many felt obligated to visit their relative daily. For some, these feeling of guilt and burden left them unable to consider future treatment options for the dying resident, focusing instead on day-to-day activities (Forbes et al., 2000).

Staff Support

It is important that death is recognized as significant event for staff as well as families. Long-term care staff reported feelings of sadness and inability to accept the death of a resident (Rickerson et al., 2005). Staff were drawn into the grief experience as they develop caring relationship with residents (Brazil et al., 2004). In a description of a long-term care palliative care unit in France, it was explained that unit staff there had the opportunity to speak with a psychoanalyst regularly. The psychoanalyst allowed them the opportunity to talk about the difficulties they experienced in caring for the dying. It was felt that the psychoanalyst assisted in more open and frank discussion than would have otherwise occurred and facilitated the integration of new caregiving behaviours at the facility when appropriate (Sebag-Lanoe et al., 2003).

Caring for dying residents on a daily basis is an emotionally taxing experience, but this grief is an issue that is distinctly lacking in the literature and may be an existing service gap at many long-term care facilities. If care providers are to continue effectively

in their roles they must be supported. The CHPCA models states, “ongoing support to ensure staff’s physical, psychological and spiritual well-being is integral to the provision of hospice palliative care” (Ferris et al., 2002, p. 48). It is important that health care providers in long-term care “have access to support that enhances their ability to provide compassionate, high quality care” (Rickerson et al., 2005, p. 228) that does not cause personal detriment.

Summary

Empirical knowledge in the area of hospice palliative care service delivery in the long-term care setting has been growing in recent years. Yet, a great deal more is understood about meeting the needs of residents of long-term care facilities as they face life-threatening illnesses. Moreover, many knowledge gaps still exist. In particular, there needs to be further research into the ways in which hospice palliative care service providers can treat and minimize total pain as opposed to only the physical manifestations of pain. In addition, further exploration needs to delve into how service providers are currently striving to alleviate total pain in long-term care residents at the end of their lives and what successes they are accomplishing.

Families and service providers also have needs that must be met during the death process and during bereavement. It may be obvious to some that these groups are in need of emotional support, but according the literature reviewed, whether from a lack of resources or a lack of knowledge, these emotional needs may not always be met. Significant gaps also exist in our understanding of the challenges and barriers that service providers face when providing hospice palliative care to residents and their families in the long term care setting. There is an equivalent lack of understanding of possible

existing facilitators of the highest quality care possible. This research study contributes to the body of knowledge pertaining to quality hospice palliative care service delivery in the long-term care setting and the barriers and enhancers to providing this care.

Methodology

According to Ferris et al (2002) hospice palliative care is aimed at providing the resident with the highest possible quality of life while living with and dying from a life threatening illness. Hospice palliative care service providers strive to attain this goal by addressing the holistic needs of the resident and family, managing the end-of-life wishes of the resident, and helping the family cope with grief and loss. This study asked two research questions aimed at further understanding the methods by which service providers in the long-term care setting go about meeting the hospice palliative needs of those in their care. These questions were as follows:

1. What are the components of a quality palliative program in the long-term care setting?
2. What are the barriers and enhancers to developing a best practice palliative care program in the long-term care setting?

The following sections will provide an explanation of the methods utilized to collect the data necessary to answer each of these research questions. This will include the population studied, data collection, data collection techniques utilized, and data analysis methodology.

Population and Sample Selection

The populations studied were the long-term care facilities contracted by VAC to provide care to their residents, who are Canada's Veterans of World War I, World War II and the Korean Conflict. At present there are 171 Priority Access Bed (PAB) sites providing long-term care to approximately 4300 veterans and 1500 community care facilities providing care to another 3500 Veterans across Canada. These facilities are contracted by VAC and guarantee priority access to Canadian Veterans of World War I,

World War II, and the Korean Conflict (Veterans Affairs Canada, 2007). The staff at each of these facilities must face the prospect of caring for dying patients.

VAC facilities were selected for this study to provide a population that is able to contribute representation from facilities across Canada. Although each facility is subject to provincial guidelines and funding, these facilities also have VAC as a common contractual relationship. Representatives from the Atlantic Regional and National offices for VAC were approached to recommend facilities that provide high quality approaches to palliative care service delivery. I did not provide any guidelines by which the VAC representatives should define a “quality palliative care program” as one of the research questions seeks to determine the components of such a program. The VAC representatives identified nine facilities ideal for the scope of this study. It was recognized that these facilities were not representative of the entire population. On the contrary, VAC was asked to recommend facilities that were considered to be among the best in standards of palliative care service delivery within the VAC system.

Data Collection and Measurement

A key contact person at each of the proposed facilities was identified by the representatives from VAC. At one facility the initial contact identified by VAC continued to liaise with me throughout the study. In all other cases, the key contacts identified individuals on staff at the facilities to act as the liaison. These individuals who took on the role of liaison are hereafter referred to as the “gatekeepers”.

The gatekeeper at each facility was approached regarding access to the individual facilities. These individuals were provided with a full description of the purpose, methods, and expected outcomes of the research being undertaken. Agreement to

participate in the study was received from five facilities, one in each region of Canada (Atlantic Canada, Quebec, Ontario, Western Canada, and British Columbia). Of the five participating facilities, three facilities were dedicated to the care of Veterans alone. The other two facilities cared for a combination of Veteran and civilian residents with a specific number of beds set aside for Veterans' access. All of the facilities were large ranging in size from 175 beds to 475 beds.

Once permission had been received via the gatekeeper, the study progressed in three steps allowing for triangulation of data. A qualitative study design was used to answer the proposed research questions. Although qualitative methods are more often employed when using interpretive social science and critical social science approaches, in this case I used a post-positivist framework to answer the research questions. From the post-positive perspective there is an external reality, however, there is also an acceptance that human thought is subjective and, therefore, fallible (Trochim, 2006). With this understanding that humans contain error, all theories are revisable (Trochim, 2006). However, a belief is maintained that we should use objectivity in the search for truth even though we can never be certain that we have found this external reality (Trochim, 2006). Triangulation of data is necessary to ensure the validity of the findings (Bernard, 2000). The first step involved a policy analysis of written palliative care programs at the participating facilities. The second step consisted of interviews with facility staff based on interview guides developed from the policy analysis. Finally, field observations of palliative care service delivery aided in completing the picture of how palliative care services are delivered in the long-term care setting.

Written policies. In the first step, a request was submitted to the gatekeeper at

each participating facility for any written policies pertaining to palliative care service delivery (see Appendix A). If policies specific to palliative care did not exist, the gatekeepers were asked to submit any policy or programming documents that included palliative or end-of-life care as a component. The assumption was that even though development may not be specific to hospice palliative care at every facility, it likely existed as a component of other care policies or programs. Hospice palliative care policies were submitted for three of the five facilities for data analysis. A fourth hospice palliative care policy was submitted for another facility, but the contact asked that this policy be used by myself only to gain an understanding of the current palliative care program at the facility. The policy was under revision during the research period and was only in a draft stage. No policies were received that did not pertain directly to hospice palliative care.

Interviews. In stage two, interviews were conducted at all participating facilities aimed at understanding how palliative care policies are implemented into practice. Using the written policies received and the Canadian Hospice Palliative Care Association model an interview guide was developed for use with each of the key informants agreeing to participate. Questions in the interview guide were designed to elicit responses that aided in answering each of the research questions (see Appendix B). The interviews were aimed at obtaining further policy information and gaining an understanding of how palliative care policies are implemented at long-term care facilities. Questions were directed at services offered, gaps in service delivery, barriers and enhancers to providing palliative care services, and how the various components of the CHPCA model fit with the palliative care programs and policies at each of the participating facilities. The same

interview guide was used with participants from all facilities regardless of whether or not a written policy was received from the facility. This was done to ensure that the policy information received was consistent with the practice at each facility.

During the first stage of the study, gatekeepers were also asked to provide names and contact information for nurse managers and front-line workers who were potential candidates for participation in interviews and field observations. A management level and a front-line worker were interviewed for each facility being studied. It was thought that individuals in different positions at the facility may have a different lens through which they look at the delivery of palliative care and the effectiveness of programming resulting in different standpoints on service delivery. A total of five management level and five front-line workers were interviewed either face-to-face or by phone depending on their geographic proximity to Halifax, Nova Scotia. Two of the interviews were conducted in person and eight were conducted by telephone. Nine of the ten participants recruited for interviews were registered nurses. The management level participants included two palliative care coordinators, a resident care advocate, a palliative care nurse educator, and a nurse manager. The front-line workers included four registered nurses and one licensed practical nurse all working on nursing units at the facilities.

A full explanation of the purpose methods and expected outcomes of the study were given to each potential respondent. Although potential participants were identified by the gatekeeper, participation was voluntary. Written informed consent was obtained from all those who agreed to participate (see Appendix C). Informed consent forms were sent to potential respondents at least a week ahead of time and each person was given the opportunity to ask questions of myself before consenting to participation.

Participants in this stage of data collection were in person or by telephone, depending on the location of the facility. They were also provided with the questions in the interview guide approximately one week ahead of the scheduled interview so that they understood what would be expected during the interview and give the questions some thought (see Appendix B). Each interview was taped and transcribed verbatim.

Participant observation. In the final step of the data collection process, I attended one participating facility to undertake participant observations. Participant observation is a strategic method of collecting data in the field (Bernard, 2000). In this case I adopted the role of the observer-as-participant (Ruben & Babbie, 1997). Using Gold's terminology as cited in Ruben and Babbie (1997), an observer-as-participant is someone who participates fully with the group being studied, but makes it clear that research is being undertaken. I was an outsider who came into the facility to observe front-line workers as they performed their daily care tasks. My previous work experience within the acute care and long-term care settings allowed the observations to take place while helping the unit staff with various tasks when the opportunity arose. This most often happened when the staff member being observed was working with a resident who had not consented to participation in the study.

Before data collection could commence during this stage, I was required to receive ethics certification from the facility participating in this stage of data collection. The ethics application was supported by the gatekeeper for the facility and nurse manager for the unit proposed for participant observations. Following the receipt of ethics certification, the gatekeeper recommended front-line workers to be invited to participate in this stage of data collection. Two registered nurses and one licensed practical nurse

were recruited to participate. Each of the nurses was given a description of the study and the informed consent forms ahead of time allowing sufficient time to read the forms. They were also given the opportunity to ask questions of myself about their participation (see Appendix A). The informed consent was received before commencing the first day of observations.

Informed consent was also required from the facility residents being observed even though they were not being shadowed. The unit charge nurse aided in determining which residents could provide consent for themselves and which residents required the authorization of next of kin for participation. The two registered nurses recruited for participation initially approached the unit residents to determine their interest in participation. As the facility residents were considered to be a vulnerable population, intermediate contact by the nurses was a stipulation required in the ethics certification. In the week prior to commencing participant observations, the unit was visited twice for two hours at a time to answer residents' questions and obtain informed consent (see Appendix C). Contact information was provided on the forms in case family members who were not present during these visits had questions about the study. Of the twenty-six residents on the unit, thirteen residents were agreed to participate in this stage of data collection. Of these two required the authorization of family members to participate due to cognitive status. One resident declined participation. The remaining residents were excluded from the study, because they suffered from cognitive decline and family members were unavailable for informed consent.

Participant observations took place over four days with one front-line worker being shadowed per day. The participants were shadowed for one twelve hour weekday

shift, one eight hour weekday shift, one four hour evening shift, and one twelve hour week-end shift. Field observations, which took place during varying times of the day, aided in understanding how resource allocation may vary over the course of the day and the week.

Of particular interest was how policies and programs were put into practice on the unit. Observations focused on understanding the characteristics of those receiving care including their health status, symptoms, and holistic needs as well as identifying enhancers and barriers to quality hospice palliative care given these characteristics. Also of concern was observing the interactions between unit staff and residents and how these interactions affect the quality of care received. Two methods of data collection were used during participant observation. First, an observation plan was developed using the CHPCA model, the received written policies, and interview transcripts (see Appendix D). In addition an observation tool was developed to help observations as they occurred (see Appendix D). To ensure accuracy and ease of observations this tool was carried at all times during field observation.

Three methods of data collection were used during participant observations. First, observation notes or *jottings* were used to document the various activities that took place over the course of the day. Jottings are brief notes taken during shadowing. “They are short, temporary memory triggers such as words, phrases, or drawings” (Neuman, 2003, p. 384). These jotted notes were taken during the shift, whenever there was time to write down relevant details. In particular, this occurred during breaks or when the front-line worker was providing care to a resident who had not consented to participation. Jottings were noted under the headings outlined in the observation tool developed. One nurse was

followed per shift and took quick, point form notes were taken of the nurse's actions and interactions.

During the course of each shift, I conversed frequently with the individual being shadowed. Such conversations occurred between rooms and during breaks, and they took the form of unstructured interviews (Neuman, 2003). Whenever possible, questions were directed towards the context of care, the needs of residents receiving care, the effectiveness of the care provided, and difficulties experienced in providing care. Detailed notes of these conversations were taken alongside the observation notes. These informal interviews constituted the second method of data collection.

Finally, immediately following the end of a shadowing shift, direct observations notes were recorded. These are a detailed description of the events and activities of the day (Neuman, 2003). The jotted notes were used to trigger memory and provide more detail in this section. To decrease potential memory loss, direct observation notes were completed as soon as possible following a shift. These notes also aided in determining when data saturation had occurred.

Before leaving the facility at the end of each day a few minutes was spent debriefing the shadowed worker. This was often very quick as the shadowed workers typically wanted to be heading home as soon as possible following their shift. However, this debriefing allowed the worker to voice any concerns about the events of the day and to ask any questions about the research being undertaken. The worker was supplied with contact information in case he or she had questions or concerns at a later date.

Data saturation was obtained following four shifts at the facility. Debriefings took place at the end of each shift with the workers being shadowed. Following the completion

of the entire shadowing period the research met briefly with the gatekeeper to let her know that data collection was completed and this meeting occurred in person. The purpose of this meeting was not to discuss observation notes, but rather to notify the gatekeeper that I would be exiting the field and to further address any questions or concerns the gatekeeper may have had at the completion of data collection. He or she was also offered a timeline for the dissemination of a final report.

Data Analysis

Collection and analysis of written policies, interviews with managers and nurses, and participant observations were all necessary to ensure that research findings are valid. As previously noted, this research project employed a qualitative research design. Qualitative research data analysis is often influenced by the bias of the researcher. In interpretive and critical social science paradigms of thought, this bias is recognized and embraced. Different researchers may analyze data very differently, depending on the criteria used in analysis (Bernard, 2000). However, in a project where the main goal is the assessment of quality care for a broad population, the highest possible level of objectivity is required, even though the data collected is qualitative in nature. For this reason, policy analysis was conducted using specific criteria laid out in the CHPCA model.

Policy analysis. Palliative care policy at each of the participating facilities was analyzed to comprehend several aspects of policy development. These aspects were uncovered and understood in the following order within the context of the CHPCA model: (a) problem definition, (b) policy goals, (c) instrumentation, (d) implementation, and (e) outcomes (Pal, 2001).

The problem definition is the central element of any policy. Policy development

begins with the identification of a problem. The problem definition generally describes this problem and defines it along with a set of causal factors. The policy is developed and implemented to manage the defined problem (Pal, 2001). An understanding of how the management of a long-term care facility views and defines the care of terminally and chronically ill residents is necessary in order to understand how palliative policy has been developed and implemented. The first step of the process towards gaining such an understanding was the identification and comprehension of problem definitions as they apply to palliative care service provision.

Once the problem definition was analyzed, I began to consider the goals of the policies being analyzed. Policy goals may not always be specifically written into the policy; they may need to be inferred (Pal, 2001). For example, one of the main goals of hospice palliative care is to “relieve suffering and improve the quality of living and dying” (Ferris et al., 2002, p. 17). Although the improvement of quality of life may not specifically be written into a policy, the alleviation of pain and other discomforting symptoms may be a central component. Because pain and symptom management is aimed at improving the quality of life of a resident, it may be inferred that this is one of the overarching goals of the policy. The palliative care policy goals and objectives of the participating facilities were analyzed using the CHPCA model as a framework for analysis.

Policy instruments are “the means chosen on how to address the problem and achieve policy goals” (Pal, 2001, p. 35). The instruments chosen to put the policy into practice are the “how” component, but they are distinct from the implementation process (Pal, 2001). For example, the facility may decide that pain and symptom management

should be prescribed by an attending physician. This is the instrumentation. The implementation is the actual hiring of a physician and the practice of the physician meeting with residents and prescribing treatment. If a physician cannot be found the instrument has been selected, but not be implemented. The research questions asked in this study focused on identifying the components of a quality hospice palliative care program and the barriers and enhancers to delivering such a program. These questions were answered through the analysis of the instrumentation and implementation of each of the programs studied.

The outcomes are the actual effect that implementing a policy has on the problem (Pal, 2001). In this case, the outcomes are the effects that the palliative care programs and services have on the residents and families at long-term care facilities. This aspect of analysis is touched on only briefly in this study. For the most part, policy outcomes are beyond the scope of this research design.

The method of policy analysis used to assess quality in palliative care service delivery in the long-term care setting was *normative analysis*. Normative analysis is used to “analyze policy in reference to basic values or ethical principles” (Pal, 2001, p. 17). Policies and practice at each of the participating facilities were evaluated to determine if they were consistent with the values and guiding principles of the CHPCA model. These values and principles may not be specifically written into policy, so a deduction occurred through all three steps of data collection if the values and guiding principles of the model are adhered to or if gaps exist. In doing so, I also attempted to determine which components of the CHPCA model are consistent with hospice palliative care service delivery in the long-term care setting.

Written policies. In the first stage of data analysis the three written policies received were analyzed to deduce problem definition (see Table 1), policy goals (see Table 2), and instrumentation. The policies were then compared to the CHPCA model to determine where service gaps existed, where services provided had improved upon the model, and where services provided in long-term care differed from other care settings. Policies received were also compared to one another. Comparison of policies between institutions helped to identify what services most facilities were able to provide and where gaps in service frequently existed. These services and potential service gaps were used in combination with the CHPCA model to develop an interview guide for use in the second stage of data collection.

Table 1

Palliative Care Policy Definitions by Long-Term Care Facility

Facility	Problem Definition
1	“Palliative care [at this facility] is that care which is given by an interdisciplinary health care team to patients/residents in their last stages of a chronic and/or terminal illness when treatment aimed at cure and prolonging life is no longer appropriate.”
1	“Palliative care is the compassionate, holistic care of individual patients/residents for whom care is concentrated on comfort, control of pain and other symptoms and the provision of spiritual, psychosocial and emotional support of patient/resident, family, volunteers and staff.”
1	“The palliative care consultation service is developed and implemented by a specially trained interdisciplinary team who will work on a consultative basis with other staff members. The team members will maintain a close link with community palliative care services.”

(Table 1 continues)

Facility	Problem Definition
2	“The Palliative Care Program seeks to complement existing clinical service in Long Term Care for Veterans and their families affected by a life-threatening illness, a loss, or a health crisis. The intent of the Program is directed toward the greatest possible relief of suffering and the highest possible quality of life for both Veteran and family.”
3	“We at [this facility] believe that <i>end-of-life care</i> complements curative care and includes palliative care. End-of-life care necessitates an active approach with special attention to provide treatment, comfort and support for people who suffer from progressive or chronic illness that threaten their life in the short or medium term. The care provided relieves pain and other disabling symptoms. End-of-life care is responsive to the patient’s personal cultural and spiritual values, beliefs and way of life. It also includes support for families up to and including the period of bereavement.”

Table 2

Policy Goals and Objectives by Facility

Facility	Policy Goals	Objectives by Goal
1	“The goal of the Palliative Care Consultation Service is to provide support and resources to patients/residents, staff, family members and volunteers that will assist in providing care to palliative patients/residents in the [facility].”	<ol style="list-style-type: none"> 1. “To increase the opportunity for patients/residents and families to participate in the decisions made about the patient’s/resident’s palliative care.” 2. “To provide effective pain management to the patients/residents.” 3. “To minimize the patient’s/resident’s physical symptoms.” 4. “To meet the special emotional, social, and spiritual needs of the palliative patient/resident and their family.” 5. “To enhance the patient/resident and families capacity to cope with the dying process.” 6. “To enhance family and staffs capacity to cope with the death of the patient/resident.”

(Table 2 continues)

Facility	Policy Goals	Objectives by Goal
2	<p>“To complement the existing unit care team in Long Term Care meeting the needs of terminally ill Veterans by providing consultation and support to Veterans, their families, and staff.”</p>	<ol style="list-style-type: none"> 1. “The Palliative Care Program consisting of an Interdisciplinary Consultation Team of Chaplain, Nurse, Physician, and Social Worker, will seek to complement the existing unit care team and act as a resource to the unit caregivers. Members of the consultation team may be called upon: <ol style="list-style-type: none"> a. Singly or in various combinations by health care professionals, the Veterans, or their significant others. b. To address the physical, psychosocial and spiritual needs of referred Veterans and their families when terminal illness, a health crisis or loss has been identified.” 2. “The team will collaborate with other health care professionals in the assessment and delivery of holistic care.” 3. “In order to meet the individual physical, psychosocial, and spiritual needs of referred Veterans and their significant others, the team will address: <p>Veterans Care Issues by:</p> <ol style="list-style-type: none"> i. Making assessments and recommendations that are likely to promote the referred Veterans’ total comfort. ii. Employing the skills of all disciplines to identify and address social, psychological, or spiritual issues. iii. Facilitating the communication of information

(Table 2 continues)

Facility	Policy Goals	Objectives by Goal
		<p>to Veterans relating to their disease, prognosis, and dying process.</p> <ul style="list-style-type: none"> iv. Providing support for referred Veterans during the transitional phase of their illness. v. Continuing to train and have input into volunteers who will serve as “friends” to the Veterans throughout the remainder of their lives. <p>b. Family Care Issues by:</p> <ul style="list-style-type: none"> i. Involving families in the care of Veterans, and insuring maximum time for the Veterans and their significant others to be together. ii. Helping family members accompany Veterans throughout the transition phase, and encouraging the working through expressions of grief BEFORE as well as after death. iii. Maintain the program of trained volunteers who will help support family members during the Veterans’ illness and participate in the Long Term Care Bereavement Follow-up Program. iv. Providing resource counseling in the line of legal, financial and funerals as required by families. <p>c. Support for Caregivers by:</p> <ul style="list-style-type: none"> i. Encouraging open dialogue, and assisting in meeting the needs of caregivers in experiencing grief. ii. Being available as palliative care resource personnel.

(Table 2 continues)

Facility	Policy Goals	Objectives by Goal
2	<p>“To maintain the Bereavement Follow-up Program at its current high level of quality delivery by means of staff education and volunteer components of service.”</p>	<p>iii. Continuing to participate in staff orientation and educational programs, and encouraging staff on each unit to become increasingly involved in the theoretical and clinical aspects of palliative care.</p> <p>iv. Supporting the concept that care requires the collaboration of many disciplines working as an integrated clinical team, meeting for frequent discussions and with a common purpose.”</p> <p>1. “To provide ongoing education of Bereavement Follow-Up Program, determining further needs on the basis of input from loved ones and caregivers, and implementing suggestions where applicable.</p> <p>2. To continue to provide staff educational programs by collecting and making available resource material, planning and implementing in-services, workshops, seminars, and small discussion groups.</p> <p>3. To maintain the volunteer service by recruiting, screening, educating, and placing volunteers, upon request of the health care professional, Veteran, or family.</p> <p>4. To monitor the effectiveness of volunteer interactions, and to provide ongoing support and educational opportunities for volunteers.”</p>
2	<p>“To liaise with the Palliative Care Coordinator at the [local acute care hospital] in order to consult on educational, medical, volunteer, and pain-related</p>	<p>1. “To maintain and enhance lines of communication between the Acute and Long Term Care settings of the Palliative Care Program by frequent personal, telephone, and/or written contact.”</p>

(Table 2 continues)

Facility	Policy Goals	Objectives by Goal
	issues (assessment, management, and development of guidelines).”	
2	“To facilitate and promote better understanding of palliative care throughout professional and lay communities.”	<ol style="list-style-type: none"> 1. “Internal- to acquaint the rest of the hospital with the Palliative Care Program, keeping all departments informed of new developments (eg. Educational) by means of notices, newsletters, and brochures. 2. External- to continue to acquaint the community with the program by means of media campaigns and speaking engagements with community groups.”
3	“To improve the patient’s quality of life by easing all aspects of pain and suffering.	
3	“To support the patient in his journey towards death by offering emotional and spiritual comfort.”	
3	“To grant the patient’s final wishes and respect his choices so that he may die with dignity.”	
3	“To offer support to family members and share with them the responsibility of providing for the patient’s needs.”	

Interviews. Once written policies were analyzed and an interview guide developed (see Appendix B), interviews commenced. Normative analysis of this section of the data collected was undertaken using the principles and norms of practice included in the “Square of Care” section of the CHPCA model. This section include principles and norms of practice guiding assessment, information-sharing, decision-making, care planning, care delivery, and confirmation (Ferris et al., 2002).

Transcribed interviews were analyzed using QSR NUD*IST software. Themes, categories, and sub-categories were developed to help answer the research questions. For those facilities where written policy exists, a comparison of the written policy and the actual practice, based on interview answers, was also undertaken. The purpose of this comparison was to evaluate consistency, look for gaps in service, and identify services that existed above and beyond written policy. Preliminary findings resulting from normative analysis of the written policies and interview data were used to develop the observation plan and observation tool used in stage three of data collection.

Participant observation. The analysis of written policies was aimed at determining how each facility planned to deliver palliative care services. Interviews helped to expand on this and provided insight as to how services were actually delivered. Interviews also helped to gain an understanding of the challenges faced by the individuals delivering this type of care and the strengths that each of them felt they had to offer. It was anticipated that there would be distinct differences in responses concerning services available and how services are delivered between nurse managers and personal care workers. It was also anticipated that interview responses might reflect the standpoints of those interviewed, but may not provide an overall picture of how services are delivered at the unit level. Thus, participant observations were aimed at providing me with a first-hand look at how policy was put into practice.

All field notes were typed and entered for analysis in QSR NUD*IST software. The field notes were coded into the existing themes, categories, and sub-categories and new categories and sub-categories were developed where appropriate. Once coding of all interview and observation data was completed the themes, categories and sub-categories

were subjected to normative analysis again using the CHPCA model as a framework for analysis.

Findings and Discussion

Currently, there is little research available relevant to defining a quality hospice palliative care program in the long-term care setting. Without the availability of such a definition, it is difficult for care providers and administrators to assess quality and standards in this area of care in this unique care environment. The first question of this research study asked what components of care constitute a quality hospice palliative care program in the long-term care setting.

Components of Care

The CHCPA model includes several domains of care for hospice palliative care service delivery. These are disease management, physical, psychological, social, spiritual, practical, end-of-life care/death management, and loss/grief. Each of these domains is considered when caring for a dying resident at each of the participating facilities, but facilities may be stronger in some areas than in others (Ferris et al., 2002). Based on the written policies received, interview responses, and participant observations the current practice at each of the participating facilities is consistent with the components of care included in the CHPCA model.

Disease management includes diagnoses, co-morbidities, and adverse events. In most cases the participants in this study were not directly involved in diagnosing residents. However, they were responsible for assessing residents on a regular basis and consulting with specialists, including physicians, who could make the appropriate diagnoses (Ferris et al., 2002). Key informants in the study indicated they generally had ready accessibility to all necessary specialists when delivering hospice palliative care. This is significant as at least one Canadian study (Brazil et al., 2004) has found that

ongoing assessment of residents and the availability of specialist consultations were determined to be important components of disease management. Failure to recognize imminent death was reported by service providers in this study to be a barrier to quality care.

Physical care includes management of pain and other discomforting symptoms, function, nutrition, and wounds (Ferris et al., 2002). The front-line workers participating in this study were actively involved in this component of care and felt that this was one of the most important components of their role as care providers. This is consistent with the findings of a focus group study that reported that frontline workers stressed the importance of managing common symptoms in dying residents (Brazil et al., 2004). As a group, frontline workers in this study felt that the physical needs of the resident were the easiest needs to meet. However, although study participants felt they were able to effectively meet the physical needs of their residents, it is important to remember that this is only one perspective. The perspectives of residents, family members, and specialists are required to fully understand if the physical needs of residents at VAC facilities are being met. For example, in a study of cancer patients residing in nursing home 24-38% of residents studied experienced pain on a daily basis (Bernabei et al., 1998). In addition, at least one key informant in this study felt that pain assessment in residents with dementia was an ongoing challenge in the long-term care setting and an area that required increased attention by researchers in the field. This nurse stated, “Probably one of the biggest challenges around is trying to find a [pain assessment] tool that someone with dementia is able to participate in and certainly that’s huge”.

Psychological care includes behavioural issues, depression, anxiety, emotions,

fears, dignity, independence, and self-esteem (Ferris et al., 2002). Brazil and colleagues (2004) reported that frontline workers expressed the importance of fostering respect and dignity as components of a “good death”. The written policies analyzed all included psychological care and emotional support as central components of hospice palliative care. For example, one policy provided an objective requiring staff, “to address the physical, psychosocial and spiritual needs of referred Veterans and their families when terminal illness, a health crisis or loss has been identified”. Most key informants felt that strides had been made in recent years towards improving this area of care for residents facing terminal illnesses. However, many also felt that in comparison to physical needs, it was much more difficult to meet the emotional needs of residents and that improvements in this area were still necessary.

The hardest [needs] to meet [are] probably like I said the emotional ... the psychological pain...you know sitting down and ...there are a few people who can really address that but I think the majority don't. Because they're not comfortable with it.

Emotional support for the family has also been reported to be of great importance according to service providers (Brazil et al., 2004). In discussing this component of care with key informants, several indicated that the primary focus was the resident him/herself, but that both frontline workers and specialists did strive to meet the emotional needs of the family as well. Most front-line worker key informants felt better equipped to support the emotional needs of the resident than those of the family. However, they did indicate that it was not entirely their role within the care team to provide this care. It was pointed out that pastoral care workers, social workers, and psychologists were often available to provide support to the family. However, when probed, several key informants acknowledged that meeting the emotional needs of the

family was an ongoing challenge in the long-term care setting.

The problem is when it comes from a day-to-day care and going into end-of-life care, because sometimes we don't know when it's starting... Sometimes it's clear, but [sometimes] it is not clear... [Dying] can last long or it could be very flat, very short and that's the hardest part for us to cope with and with the family- to help the family cope with...[a fast] situation of dying.

Social care includes cultural values and beliefs, relationships, family roles, friends, community, isolation, privacy, recreation, financial resources, legal issues (advance directives, last will and testament, powers of attorney), guardianship, and custody issues (Ferris et al., 2002). In one study reviewed (Brazil et al., 2004), service providers participating in focus groups expressed the importance of recognizing cultural values and providing social support to residents and families facing life threatening illnesses. These service providers also stressed the importance of privacy and a comforting atmosphere. Although none of the written policies collected refer specifically to respecting culture, all note the importance of the personal choices of the resident and the perspective of the family. The wording of the policies is broad, but does state that individual choices and customs should be adhered to. For example, one policy states its aim, "To grant the patient's final wishes and respect his choices so that he may die with dignity". It was assumed in reading these policies that cultural practices would fall under the umbrella of individual wants and needs.

To confirm this assumption, key informants were asked how they went about ensuring that the cultural values of residents were respected. Responses reflected on the wide variety of cultural backgrounds that were encompassed in the facilities participating in the study. Key informants felt that often social workers and pastoral care workers could provide some guidance in this area. However, most often key informants felt it was

best to have the input of the family when trying to understand the cultural values of residents from diverse or minority backgrounds. One nurse reflected, “I think that once we know that there is a different culture... we’re able to talk with the family and just talk about what needs to be done”.

In terms of social well-being, several key informants expressed that one of the benefits for Veterans living in a VAC was a sense of community. Although post-war many residents at the participating facilities went on to non-military careers, residents who were Veterans shared a common experience in the wars they fought. Still, some key informants found that some residents felt isolated from the community for a variety of reasons including social background, cultural background, and declining cognition. In most cases, the isolation experienced could be lessened through family visits, time spent with unit staff, and activities with the recreation programs at the facilities. For some individuals, these were not enough to solve the social pain caused by feelings of isolation. This was seen in one resident during participant observations. The resident suffered from post-traumatic stress disorder, early stage dementia and was confined to a wheelchair. During time with me, he disclosed that he used to be able to spend time on his own, but had become afraid to do so. Unable to visit often, the family had hired private care workers to come into the facility during waking hours to spend time with this resident. During field observations, front-line participants explained that volunteer companions were available at the facility to spend time with residents, but were not available for the length of time that this resident required.

Key informants were not involved in all aspects of social care. When asked, they generally felt that social workers were able to provide a wide range of insight and support

to families when it came to many components of social care including family roles, financial resources, legal issues, guardianship, and custody. Social workers were not interviewed in this study, but this role was referred to in the written policies as members of the care team and was mentioned by most key informants.

Spiritual care includes meaning and values, beliefs, practices, affiliations, spiritual advisors, rites, and rituals (Ferris et al., 2002). Service providers indicated that religion and spirituality could be of benefit to residents faced with life threatening illness. In particular, the provision of spiritual support was reported to provide a sense of comfort to these residents (Brazil et al., 2004). This sentiment is reflected in the written policies analyzed. All policies list spiritual care as one of the central components of hospice palliative care (see Table 2). Key informants discussed the ready availability of pastoral care workers on a 24-hour basis in times of crisis and their regular presence on the units for the provision of spiritual care to all residents who so desire. When asked about the availability of pastoral care, one key informant replied, “We actually have 1.5 [full-time equivalent] of spiritual care in our facility and one of those people is assigned to be the chaplain of the Veterans. So they do lots of work down here with spiritual care”.

In addition to pastoral care workers employed by the facilities, key informants noted regular visits to residents by rabbis and priests from the community. Several key informants stated these spiritual advisors were easily accessible for consult and care provision as needed. The availability of chapels for regular religious services within each of the facilities was also discussed as well as the importance of the family in providing guidance for religious rituals at the end-of-life when staff was not familiar with the specific practices.

Practical care includes activities of daily living (personal care), dependents, pets, telephone access, and transportation (Ferris et al., 2002). This component of the CHPCA model is perhaps the one component that does not fit entirely with the hospice palliative care policies at the facilities studied. One key informant pointed out that in recent years there has been a change in the characteristics of individuals being admitted to VAC facilities. She felt that there had been a shift in policy to a focus on caring for Veterans in their own homes for as long as possible. This key informant reflected that newly admitted residents were more frail and suffered from a greater number of co-morbidities than used to be the case. Similar observations were noted by other key informants as well. As a result, individuals require this practical care including assistance with activities of daily living from the time they come into the facility regardless of whether or not they are faced with life threatening illness. Practical care is considered a component of general care policy at the facilities. To a certain extent, this is true of most components of hospice palliative care, but more so with practical care. Practical care does not seem to require specialist knowledge in hospice palliative care to the extent of other components of care.

End-of-life care and death management includes saying good-bye, legacy creation, preparation for expected death, anticipation and management of physiological changes in last hours of life, rites, rituals, pronouncement, handling of body, funerals, memorial services, and celebrations (Ferris et al., 2002). All of the components laid out in the CHPCA model for end-of-life care are adhered to by the facilities studied. The instruments for meeting end-of-life needs were wide ranging and at the same time individualized for each resident and family. For example, key informants told many stories of how they helped families to say good-bye. One in particular stood out, because

the nurse spoke of a woman who was afraid to approach her father's room during the last hours of his life. The nurse said she encouraged the woman to enter the room and then hold her father's hand. She said she thought this was a very healing experience for the woman.

According to the key informants, each of the facilities held regular memorial services to remember those residents who had recently passed and staff were encouraged to attend the funeral services of residents. During participant observations, it was noted that in the main lobby of the observation facility a large book was placed in a glass case. Each resident who had lived at the facility was listed with the date of their death in beautiful calligraphy. Outside the facility, large slabs of black marble were placed around a memorial garden. The name of each resident who had died at the facility was engraved on the marble along with their rank, the unit they served in, and the war or wars they fought. These were examples of ways in which facility staff ensured that the Veterans were not forgotten after death.

Loss and grief care includes emotional support, bereavement care, and mourning (Ferris et al., 2002). Based primarily on key informant interviews, although loss and grief was a recognized component of hospice palliative care, there was a much higher focus on caring for the resident. Loss and grief care was an area that was primarily being developed at most of the facilities studied. Family and staff support are areas that will be discussed in greater detail in subsequent sections, but the relative lack of bereavement care and family support apparent in this study was consistent with other findings to date (Vohra et al., 2004). Families surveyed indicated that while they were happy with the overall quality of care their dying relatives received, some of the lowest satisfaction

ratings received were for family support (Vohra et al., 2004).

Implications of Components of Care

Each of the participating facilities were identified for inclusion in this study by representatives from VAC because they were considered to have high quality hospice palliative care programs. “High quality hospice palliative care” was not a term that was defined in this study. Instead, it was anticipated that the term would be defined through analysis of the programs at these facilities. With this assumption in mind and based on the written policies received and interview data obtained, high quality in hospice palliative care can be achieved in the long-term care setting through application of most components of care found in the CHPCA model. Although, this is a very limited data set, most of the domains of care included in the CHPCA were considered by the key informants interviewed to be important components of any quality hospice palliative care program in the long-term care setting.

The domain of care in the CHPCA model that may be an exception to the model’s applicability is *practical care*. As previously suggested, practical care, such as telephone access, assistance with activities of daily living, and transportation, was arranged for long-term care residents whether or not they are faced with a terminal illness. It may not be necessary to include practical care in an overarching palliative care program for a facility. It could be argued that many other domains of hospice palliative care are also applicable to the general care of all residents, not just those who are palliative. However, the other domains have a tendency to be altered in the care plan and require the attention of hospice palliative care specialists when a resident is faced with a terminal diagnosis. The same is not true of practical care.

Although data collected indicated that the domains of care included in the CHPCA model were consistent with what was considered to be ideal components of a quality palliative care program at the participating facilities, key informants indicated that the facilities were stronger in some areas than in others. In particular, key informants felt the best prepared to deliver physical care. Most key informants felt less prepared to deliver social, emotional, and spiritual care, but several indicated that there had been improvements in these areas in recent years. This may be an indicator that dedicated hospice palliative care educational programs may further assist front-line workers in delivering components of care outside of physical care.

It should be noted that it is not reasonable to expect front-line workers to fulfill every role necessary to meet the holistic needs of residents. However, educational programs could help these workers feel better equipped to meet needs outside of physical care until specialist care is available. Alternatively, perhaps more specialists are required on the units to fill the roles required in delivering social support, emotional care, and spiritual care.

Social support, spiritual care, and emotional care all seemed to have the attention of key informants, though they felt less equipped to meet care needs in these areas as compared to physical needs. The one area that seemed to have less focus was family support. According to the CHPCA model, family and friends are considered to be care receivers during palliation, but key informants repeatedly indicated that the primary focus of their care was the resident. This is not to say that family received no attention. Accommodations were certainly made for loved ones when a resident was nearing death. However, family support and bereavement care were areas that were identified by several

key informants as areas that required development and improvement.

Barriers and Enhancers to Quality Care- Introduction

Having discussed what actually constitutes quality hospice palliative care in the long-term care setting, the second research question for this study asked what barriers and enhancers exist to providing this quality care. Analysis of the data collected resulted in a large number of enhancers and barriers to quality hospice palliative care service delivery. These can be summarized under six broad themes. These themes are facility hospice palliative care approach, interpersonal interactions, resident-focused care, family support, staff support, and resources. Several categories will be discussed under each of these themes.

It should be noted that in this report most themes contained many issues that are inter-related. These issues and their implications are discussed at the end of each section. However, in the case of facility approach to hospice palliative care the relevant issues are not directly related to one another. For this reason, the implications of each issue are explored directly following the discussion of the issue.

Facility Hospice Palliative Care Approach

Amongst the participating facilities there was some consistency in the general approach to the undertaking of hospice palliative care that facilitated quality care at the end of life. This consistency included policies and programming that were knowledge-based, a team approach to care, access to timely care, and collaboration with external parties that could help meet the hospice palliative care needs of residents and families.

Knowledge-based policies. The CHPCA model states that all hospice palliative care services be guided by research-based or the best available opinion-based knowledge

(Ferris et al., 2002). According to the written policies and key informants the facilities involved in this study each used a specified care model to guide policy development, programming, education of staff, and service delivery. In two cases, the policy developers used the CHPCA model to guide hospice palliative care programming. Other models included Gentlecare (Jones, 2007), the Eden Alternative (Thomas & Thomas, 2007), and a facility-specific model developed by the research and education committee at the facility. Using an overarching framework to guide all aspects of hospice palliative care facilitated quality care through consistency and standardization of programs, staff education, and service delivery (Ferris et al., 2002).

Implications of knowledge-based policies. Based on the written policies received and key informant interviews, the use of knowledge-based model to guide care is an enhancer to quality hospice palliative care service delivery. Although only two of the facilities used the same model, all facilities included in this study used an overarching framework to guide hospice palliative care service delivery. All key informants felt that the model implemented at their facility was effective. Based on this evidence, it may not be necessary to have one standardized model to guide hospice palliative care at all facilities. Alternatively, policy makers at individual facilities should find a knowledge-based model that is appropriate to the effectively meet the needs of their resident population.

Team approach to care. When asked about how facility staff strove to meet the holistic needs of residents and families all key informants discussed a team approach to care. The team itself looked somewhat different depending on the facility. Each facility utilized the resources it had available to develop their teams in different ways. There

were often two separate teams that collaborated with one another to meet the hospice palliative care needs of each resident. The first team was the unit team and the second was the hospice palliative care inter-disciplinary team.

Key informants explained that the unit team consisted of the front-line workers and specialists who provided direct care to residents on a daily basis. At some facilities personal care workers provided the bulk of daily care, whereas other facilities employed only licensed practical nurses and registered nurses to undertake this role. Personal care workers and nurses were able to consult regularly with specialists within the facility to meet the holistic needs of the residents. These specialists included physicians, psychologists, occupational therapists, physiotherapists, dieticians, pastoral care workers, recreation therapists, social workers, and music therapists. Participating facilities also had volunteers available to them to act as friends or companions providing social support to residents. This is not an exhaustive list as there were many individuals included on the care team. Some facilities considered house keeping and laundry personnel to be a part of the care team and included them in care planning. This team approach is consistent with Berger's (2001) opinion that there is no medication that addresses total suffering and that holistic care requires the attention of a team of specialists providing non-pharmacological treatments.

Key informants felt that regardless of the titles of the people providing care, each person involved in care was aware of his or her role on the unit. Key informants talked about the unit staff being able to work as a team, to cover for one another when one resident required extra attention, and to act as emotional supports to one another when dealing with difficult situations with residents and families. When asked how unit staff

coped with grief after the loss of a resident, one nurse stated,

I guess that's an individual thing... there's no specific [policy], except that we always support each other... you're all together in it. I guess there's a very good team spirit. At least there is on my particular unit... so you know we support each other in that way.

Another nurse discussed how when a resident is nearing the end of life she will take the time to sit with the resident until the family is able to be there. When asked if she has enough time during her shift to do this, the nurse explained that it was the support of her co-workers that enabled her to provide this social support.

Well, at that time, [when someone is dying] like I've got no time. I just say to my co-workers, I will be in that room until the family comes... And it's like they'll know. Usually, we do have... support from our co-workers for that. It's pretty good.

During participant observations one incident illustrated how a break-down in unit team cohesion could be a barrier to quality care. At the beginning of the shift the participating nurse was assigned to half the residents in one hallway on the unit. The participating nurse approached the other nurse who would be working in that hallway to see if she would like to work together on all of the residents in the hallway, but the nurse declined. The participating nurse said that the other nurse seemed to feel that she was trying to give the other nurse some of her work, then stated that she would still attend to any needs that arose along the hallway regardless of who the resident was assigned to. She said she did not want to ignore anyone who needed help.

During the course of the day the participating nurse carried out her regular daily tasks with her assigned residents, but also responded when residents assigned to the other nurse called for help if the other nurse was not available immediately. She did not allow her level of care to decline when working one on one with residents, but was visibly

frustrated with the increased work load for the day. In this case, the other nurse was a casual worker who was only on the floor for the day filling in for a regular staff member. However, if a situation like this were to occur consistently, the frustration felt by the nurse with the increased workload could eventually impact on the quality of care received by the residents. This situation effectively demonstrated the importance of team work and how it could enable unit staff to meet resident needs as they arose.

Leadership within the unit team was also necessary to ensure that individual needs were observed and met. During key informant interviews, participants from two facilities discussed primary care assignments given to each nurse on the unit. Primary care assignments were residents who were individually assigned to a specified nurse. The nurse was then responsible for ensuring that the care plan for that resident was kept up to date, that the resident's needs and wishes were attended to, and the resident's family was kept informed of any changes in the health status or care plan for the resident. The nurse became a leader in advocating for any residents he or she was assigned. This role gave increased responsibility for each resident on the unit to one person. The number of residents assigned to each nurse varied between facilities.

The primary care assignment enhanced quality care by improving continuity of care and providing an advocate for the individual needs of each resident. It is important to note that although this role may be a great enhancer to quality care, the primary care assignment was not mentioned during interviews by participants from all facilities. This does not necessarily mean that these facilities did not make use of such a position. For example, the primary care assignment was not mentioned during interviews with participants from the facility participating in field work. However, during participant

observations it was learned that the facility does in fact make use of the primary care assignment.

The unit team was an integral part of care whether or not the resident is faced with a life threatening illness. However, participants noted that unit staff were not typically specialists in hospice palliative care and often needed advice as to how to effectively carry out care for a dying resident. It has been suggested that even though specialist care is required, residents maintain a better quality of life when they are cared for “in place” rather than being moved to a hospice palliative care unit (Sebag-Lanoe et al., 2003). Key informants and observation participants recognized that they had often been caring for the dying residents for extended periods of time, sometimes for years, and that they knew their residents very well. This practice demonstrated an understanding that residents would be most comfortable at the end-of-life being cared for by the facility staff who had cared for them all along. All five participating facilities had hospice palliative care teams that acted as a consultative and complimentary service to the existing unit team. Consequently, the residents were not moved away from the care providers they knew to be cared for by specialists.

The shape that the hospice palliative care team took at each of the facilities varied. At a minimum the team included a physician, a hospice palliative care nurse specialist, a social worker, and a pastoral care worker. Many other specialists could be included on the team. At two of the facilities, the team was lead by a palliative care coordinator. This was a dedicated, funded nursing position. The palliative care coordinators were designated as leaders, advocates, and organizers of hospice palliative care service delivery at these facilities. At both facilities participants felt that having a

funded position for a palliative care coordinator greatly enhanced their ability to deliver quality care to dying residents.

The team itself could be very involved in direct care or could act only in a consultative capacity. At one facility the team was an “end-of-life” care committee that took part mostly in research and education and was available to unit staff for consultative purposes when requested. Three of the facilities had in-house hospice palliative care teams that would participate in assessment and care planning for dying residents when requested. These teams seemed to be more directly involved in care, but still left the bulk of daily care to the existing unit staff. Finally, participants from the fifth facility took a great amount of pride in the level of education in end-of-life care delivered to their unit staff.

We do a lot of education. We have an education department here... And I mentioned earlier that staff have opportunities to take that special care aide program in-house that, um, which lots of people take advantage of.

It was felt by participants from this facility that the hospice palliative care team supplied by the district health authority to all facilities in the region on a consultative basis was sufficient support to unit staff to meet the individual needs of residents. One unit nurse described the ease with which she was able to access the services provided by the hospice palliative care team at the facility when needed,

I think [the palliative care coordinator] pretty well sees everybody. And she will touch base or we'd always... have the radar on looking for a need... And re-assessing. You know assessment is just a constant thing that we do and we can call upon the palliative care coordinator [or] any of the other services really at almost anytime.

Regardless of the shape of the hospice palliative care team or the level of its involvement,

all key informants and observation participants felt that residents received the best care when cared for by existing unit staff who were supported by a team of specialists who could provide consultations as needed.

Implications of team approach to care. Fostering a team approach to care was deemed to be an enhancer to quality hospice palliative care. The composition of the team changed depending on the resources of the facility, but even when there were fewer resources working as a team served to ensure that gaps in service delivery were minimized. A team approach enhanced care through ensuring that individual residents had dedicated care at the end-of-life while other residents on the unit were still attended.

Key informants also expressed that the team approach meant that all team members had similar experiences and could act as emotional supports to one another. These emotional supports enhanced care by allowing front-line workers an emotional outlet that in turn helped them to avoid burnout and continue in their daily roles. In addition, key informants felt that a team approach allowed everyone involved to be aware of their roles in care and that this enhanced care by further decreasing gaps in service delivery. Contrary to the team approach, when individuals worked against the team approach it was seen to be a barrier to quality care. Managers within long-term care units should be looking for methods of fostering group cohesion in positive ways that contribute to the high quality care of residents and their loved ones.

Leadership within the team can also be deemed to be an enhancer to quality care as it furthers the team approach to care. Designated leaders, such as hospice palliative care coordinators, enhance quality care through advocacy, organization, and role identification. These things all help to minimize gaps in service and improve continuity

of care. It is also possible that the responsibilities that came along with leadership designations, such as the primary care assignment, empowered unit workers in their roles and encouraged them to deliver higher quality care to those in their charge.

Finally, the existence of a specialist hospice palliative care team within the facility or the region was seen as an enhancer to quality care. The existence of such a team ensured that most residents could be cared for in place by care providers they knew while still receiving the benefits of specialist care at the end-of-life. Again, the shape of the hospice palliative care team was influenced by the resources available to the facility. It seems that the use of a palliative care team as a compliment to the care of the unit team enhances care through maintenance of continuity of care and surroundings that are familiar and assumedly comfortable to the resident. Policy makers need to be aware of what resources they have available to them in the region or community, so that they can build care teams that fill gaps in service and compliment existing care teams.

Based on these findings, hospice palliative care programs should be developed in ways that support the existing unit team to care for residents as they transition into palliative care instead of moving residents into separate hospice palliative care units. This can be done through fostering a team approach to care on the unit and developing specialist hospice palliative care teams that provide the support to the unit team. This support can be provided through complimenting existing services and providing consultation and advice to existing unit staff. Managers and supervisors should also look to identify key role players on the team who could act in these leadership positions and provide guidance to the team overall. Designated leaders work as advocates for hospice palliative care ensuring that end-of-life care needs are considered in the care planning

process.

Access to timely care. The CHPCA model states that residents should have access to hospice palliative care services “in a timely manner” (Ferris et al., 2002, p. 20). It is generally thought that palliative care should be implemented as soon as active treatment is no longer useful (Sabag-Lanoe et al., 2003). The question is, “When should hospice palliative care initially be offered?” There was consensus between policies reviewed that the ability to access hospice palliative care services quickly enhances their ability to deliver quality care, but there is a lack of agreement as to when the offering of these services was most beneficial. There seemed to be two considerations in attempting to determine when the resident should receive these services. The first consideration was the stage of disease progression and the second was the resident’s emotional preparedness to accept comfort care over life-prolonging or curative treatments.

The written policies differed when considering the point during the disease progression at which the resident should have access to hospice palliative care services. For example, at one facility the policy stated that hospice palliative care is offered to residents who face death in the short to medium term, whereas the policy from a another facility states that all resident should have access to these services if it is the care they desire regardless of their stage of disease progression. At the former facility key informants confirmed the written policy stating that residents have access to these services when they are actively dying. Key informants from the latter facility also confirmed the written policy explaining that the palliative care coordinator maintains an open dialogue with all residents ensuring that the care plan reflects the residents’ desires for treatment and may access her services and those of the palliative care team at any

time.

Although there is a lack of consensus with regards to the timeliness of hospice palliative care during the disease progression, there was agreement when it came to the resident's preparedness to transition to comfort care. It was firmly believed that hospice palliative care is appropriate only when the resident is ready to accept this kind of care. Several key informants described it as challenging when residents or families refused to accept that curative treatment was no longer going to be effective. One nurse explained that, "it is just so difficult to do, to be able to just listen to them, not to try to tell the what we think he should or should not do, because that's us thinking not him or her." Participants also expressed the importance of allowing residents to come to their own decisions about their care. One nurse stated,

We had a patient who was end-of-life care. He was in the room and he asked the nurses if he could go into rehab... The didn't say it that was, "But you're going to die, why would you go into rehab?" Thank God they had nurses very... palliative care oriented and she went to the physio department and she had to convince the physio department... It took him two or three sessions to say for himself, "I can't handle it anymore... Thank you very much for trying".

To facilitate a transition from curative care to comfort care many facilities incorporated flexibility into the care plans. This flexibility allowed residents to decide what level treatment was acceptable. Some residents may be ready to give up some components of full medical treatment, but may not be ready to turn completely to comfort measures only. Levels of care that incorporated elements of both curative care and comfort care were referred to as modified care. Modified care was a component of two of the written policies received and was discussed using varying terminology by all key informants and observation participants. This care planning approach enhanced resident

quality of life by allowing staff to tailor the care plan to the individual needs and desires of each resident.

This approach to care decision-making and planning was illustrated during participant observations. One resident suffered a heart attack two days before the scheduled observation shift. The participating nurse explained that the resident had not been transferred to acute care, but had instead been treated by specialists in his own room. When asked why this had happened, the nurse explained that the resident's care plan indicated his wish that he receive all measures available to him without being transferred to hospital. Upon entering the resident's room it was clear that the resident had surrounded himself with as many memories as possible in the form of photos, newspaper articles, furniture, and personal items to make his room his home. The nurse explained that the resident considered the facility his home and had a strong desire to keep living, but did not want to die outside of his home. The option of transferring to hospital to further life-prolonging or curative measures was a component of care that this resident was ready to give up, but wanted to maintain the right to all other measures. It was his choice to be treated in place and the staff respected this.

Implications of timely access to care. Timely access to care is seen by the key informants to be an enhancer to quality care, although this timing is not clearly defined. The data collected does not answer questions that may be asked about why there are differences in accessibility of hospice palliative care services or which approach best reflects the CHPCA model's request for timely access to care. However, the CHPCA model does state that care provided should be resident-focused. This allows that hospice palliative care services be sensitive to the resident's "preparedness to deal with the dying

process” (Ferris et al., 2002, p. 19). Further research may be necessary to help determine the optimal timing for accessing hospice palliative care services.

Although it is not decided when exactly in the disease progression that hospice palliative care should be offered as a treatment option, the allowance for a transition between curative care and comfort care as opposed to a clear switch in focus of care is seen as an enhancer to quality care. This improves quality care through some easing of emotional pain felt by residents and family members. Policy makers and care teams can use the *modified care* seen in two of the policies and typically practiced at the participating facilities as a guide for ensuring that residents are allowed to transition from curative care to comfort care as the disease progression and the needs of the resident dictate.

Collaboration. As discussed above, each of the participating facilities has a palliative care team in some form that collaborates with the unit team to meet the individual needs of the residents. In addition to this, each of the facilities was very adept at collaborating with organizations and resources available to them outside the facility. The CHPCA model includes a guiding principle that hospice palliative care programs collaborate with external organizations as necessary to meet the needs of residents (Ferris et al., 2001).

It has already been mentioned that one facility had no in-house palliative care team, but believed that the needs of the resident were effectively met by consulting with the team provided by the district health authority to all long-term care facilities in the region. Key informants from three other facilities also indicated availability of a regional team for consultation purposes. Other forms of collaboration to meet needs included local pain and

symptom management specialists, regionalized psycho-geriatricians, blood laboratories, and hospice volunteer organizations. This is not an exhaustive list, but does illustrate how quality care can be enhanced by collaborating with external organizations to obtain needed resources.

Implications of collaboration. Collaboration with external organizations is an enhancer to quality hospice palliative care service delivery. As programs become more developed, administrators are able to evaluate them and determine where gaps in service exist. An awareness of what resources are available in the community or region can allow facilities to make use in-house funding to be directed at what needs can not be met by these external organizations. This enhances care through an efficient use of resources.

Interpersonal Interactions

Hospice palliative care in the long-term care setting can be seen as unique, because often the care providers provide services to the care receivers on an ongoing basis for an extended period of time before they are faced with life threatening illness. Key informants in the study indicated that a resident's stay at the facility ranged on average from six months to two years. In the case of one facility, key informants said that there were some residents who had been at the facility for almost twenty years. As a result of lengthy stays, residents, families and staff have the opportunity to interact regularly and to get to know one another. These interpersonal interactions were seen by key informants to be both enhancers and barriers to quality care. The enhancers and barriers are categorized as communication, relationships, and conflict.

Communication. One of the foundational concepts of the CHPCA model is effective communication (Ferris et al., 2002). Open communication means that staff are

able to both deliver required information to the resident and family effectively and take time to listen and understand the needs of all involved (Albinsson and Strang, 2003). Based on data collected in the interviews and during participant observations, staff at the participating facilities strived to maintain an open dialogue in a variety of ways that were both formal and informal. These included care conferences, staff briefings, progress notes, and conversations during care tasks or social activities.

According to the written policies and interview data collected, care conferences were a common instrument by which all members of the interdisciplinary team came together to discuss resident needs, make decisions about treatment options and develop a care plan for each resident. Care conferences were planning meetings in which all members of the care team discussed the resident's health status and made decisions about how to proceed with care. Often the resident and his or her family were included in the care conference. This gave the resident and family an opportunity to ask questions about the resident's health status and treatment options and ensure that their needs and wishes were known to the team.

Each of the different facilities had their own guidelines regarding the timelines for care conferences. However, typically a care conference was conducted within a month to six weeks after the resident was initially admitted to the facility and every six months to a year thereafter. Ideally, in cases of a diagnosis of dementia, conversations about end-of-life care should take place soon after the diagnoses, because residents can still participate in these meetings in the early stages of the disease (Panke and Volicer, 2002). According to key informants, many residents were admitted to the facilities already suffering from dementia. It was reported that all residents were invited to participate in care planning

and care conferences to the extent that level of cognition would allow.

Although the care conference was a tool used to care plan for all residents, it was still a tool of great importance to providing quality hospice palliative care. Key informants indicated that team meetings could be pulled together very quickly when there was an acute change in health status or the resident was actively dying. The timeliness of these meetings helped to ensure resident needs were met and the family was supported during the dying process.

According to key informants, some changes in the resident's health status were small enough that a meeting of the entire interdisciplinary team was not required. In these cases, the unit staff consulted with only the necessary specialists required to meet the resident's needs. When asked about the expediency of these conferences, one key informant stated, "If we need a team meeting we certainly are able to pull it together fairly quickly and that's one of the things we do very well here". These consultations offered another opportunity for residents to express their needs and wishes and for specialists to educate residents about their health status, diagnosis, prognosis, and treatment options. When warranted and desired by the resident, these consultations resulted in changes to the care plan. When these changes occurred, all members of the care team needed to be apprised of changes in treatment. The tool that was used to ensure that everyone was kept informed was the progress notes.

Key informants discussed progress notes as a vital means of collecting data and ensuring that all necessary parties were aware of each resident's care plan. The progress notes included a wide range of information on each of the residents including diagnoses, health status, care plan, next of kin and contact phone numbers, appointments, medical

tests, likes and dislikes, social and leisure activities, activity patterns, visitors, behavioural changes, and medications. This is not an exhaustive list. The progress notes could be contributed to by anyone on the care team and included any information about the patient deemed to be important. For example, the progress notes recorded visitors, because this could be of importance to the resident's social well-being.

The progress notes could be accessed by any member of the care team and used to quickly understand current treatment and to detect changes in the resident. This was especially important for casual staff who could come to the unit without sufficient knowledge of the residents or the treatment plans. During participant observations, one of the nurses said it is important for her to review the progress notes for each of the residents on a regular basis, because the care plan could change very quickly. Especially important is a review of the medications list of each residents she is responsible for at the beginning of every shift, because for some residents the medications change daily and it is very easy to make a mistake.

It was also important for unit staff to communicate with one another about each resident even when there was no change in health status. When asked about maintaining continuity of care, almost all key informants discussed briefings that occurred at the beginning and end of each shift. At these briefings the outgoing staff briefed the incoming staff on any important events or issues for each resident. These briefings were witnessed during participant observations and included a wide variety of concerns including bowel movement, fluid intake and output, appetite, sleep patterns, energy level, behavioural issues, social activity, appointments, and treatments. Again, this is not an exhaustive list. The briefings on individual residents were sometimes as simple as saying

he or she had a good sleep. This enhanced the quality of care received by letting the oncoming staff know where the priorities and concerns for the shift may be.

The above three methods of communication were formal and completed on a regular schedule as dictated by the policies and procedures at the participating facilities. Progress notes and briefings were a means through which unit staff and interdisciplinary team members communicated with one another. Care conferences were an additional way in which the interdisciplinary team communicated both with each other and with the family and resident. However, the care conferences occurred fairly infrequently. Several of the key informants discussed a need to maintain an open dialogue with residents to ensure their needs were being addressed. One nurse was frank about how challenging this dialogue can be to attain,

Staff are not comfortable enough of saying the truth for everything, memory problems... I tell them, "You have to tell them, not blunt, but you have to say it in the way of saying 'you know you're not doing so well'..." You don't say, "You're dying of cancer. Do you know that?"... no you say something like, "How do you feel? Not so good? You don't? Yeah, you haven't been well for a while..." I'm very honest with them and they'll talk to me and when there's Alzheimer's I'll say, "Oh my God, you know, it must be hard to have memory problems." And then they open up. Because people don't confront them and so they live like in a semi-silent [world].

The ease with which some unit staff were able to communicate with their residents was observed during participant observations. For example, one resident was receiving a simple topical pain relief ointment for shoulder pain. While the nurse applied the lotion she asked him how it was working. The resident expressed a concern that it was not as effective as it used to be. The nurse let him know that there was a better one available, but it required a doctor's prescription. She said she would discuss this with his physician when she saw him during the afternoon. If the nurse had not asked the

question, she would not have known that the resident had noticed a change in the effectiveness of his treatment.

When open communication occurred during participant observations between unit staff and residents, it was easy to see how it enhanced quality of care. Asking about physical issues addressed more than the physical need. By casually asking residents about their concerns, nurses let residents know that they cared about them thus addressing some of their emotional needs as well. One of the simplest ways that this was achieved was observed when the nurses left the resident's room after providing care. Each of the three nurses shadowed would ask if there was anything else she could do for the resident. Often the answer was "no", but this simple gesture let the resident know that the care provider was there for him. The CHPCA model (Ferris et al., 2002) dictates that every therapeutic encounter should conclude with the care provider confirming that all immediate issues or concerns have been addressed. This question ensured that this component of the model was applied on a regular basis.

Relationships. Although effective communication is an invaluable tool for understanding a resident's wishes for care and treatment, not all residents are able to communicate verbally when health crises occur. According to key informants, some residents may become comatose and others, due to cognitive decline, may not be able fully understand the treatment options available to them. In these cases, decisions must still be made about how to proceed with care. With average stays at the participating facilities lasting from one to two years, unit staff have an opportunity to develop strong relationships with individuals in their care. When asked how they determine when the resident was able to make a decision and when to defer to the family, one nurse replied,

“I think we know our residents very well and really I’m speaking for most of my colleagues.” Another nurse stated her knowledge of each of the residents in her care enabled her to make recommendations for care decisions when residents could not do so for themselves, if so desired by the family or if family was not available.

In addition to facilitating decision making, relationships between staff and residents enhanced quality of care other ways. One nurse interviewed explained that an intimate knowledge of each resident facilitated accessing appropriate services. She said that doctors at the facility understood how well the staff knew the residents. She felt that when staff alerted physicians to a resident’s health issue they listened. Another nurse expressed a similar sentiment during participant observations. She said that with less than twenty-five residents on the unit, the unit staff were able to know each of the residents so well that if one of them coughed differently they noticed and were alerted to a possible issue.

Positive relationships with staff could also improve quality of care by easing a resident’s social pain. One nurse interviewed acknowledged that some personalities go better than others and assigning specific staff to dying residents could improve their level of comfort,

Some residents would prefer a certain staff and we make all the arrangements possible that the staff member they are comfortable with would stay the most. It’s not always possible on twenty-four hours obviously, but we try to make it as much as we can.

In some cases, unit staff were the only social support available to residents at the end-of-life,

You know, sometimes, especially if they don’t have family, [because] we have a few who were bachelors, they don’t have anybody and we are the only family

they have. So, in those cases we do a lot more to... have the staff they know.

As much as these relationships enhance the quality of life of residents, they can also be a challenge for unit staff. This sentiment was expressed by one nurse when she was asked how she thought challenges in hospice palliative care in long-term care differed from the challenges experienced in other care settings,

First of all... we're privileged [in] that usually we know the patient well. That means we know his history, we know who he was, we know who the family is. We can create a bond and when he dies it's like a little bit... of our family.

Another nurse felt that the relationships formed with residents could be the hardest part of her job at times,

I think... my biggest challenge [is that]... maybe there's too much empathy. Sometimes I get too involved and I have to sometimes sort of sit back a little bit and look at things... I can change some of the things, but some of the things I cannot change. And it is hard to let go, because for me some of the residents are really literally like a member of my family.

Several frontline workers expressed similar concerns about the emotional costs of caring for dying residents.

Conflict. Relationships are one by-product of interpersonal interactions. Another such bi-product of these interactions is conflict. In some cases conflict may improve quality of care. When differing opinions arise concerning how to handle a particular issue individuals have the opportunity to weigh the advantages and disadvantages of each possible option for treatment in the interest of coming up with the best possible solution. However, when conflict arises because a decision cannot be agreed upon or simply because two personalities cannot get along it can be to the detriment of the quality of care received. Based on the data collected during interviews and participant observations, within the long-term care environment conflict can arise on many levels including

between individual residents, between residents and their families, between residents or family members and staff or team members, and between the unit team and palliative care team members.

Many key informants and observation participants viewed the Veterans in their care to be a community. When individuals within the community were in conflict it was to the detriment of their social well-being and, in turn, their quality of life. For example, one key informant pointed out that privacy boundaries could be an issue in the dementia population where wandering was often a concern. Often residents who wandered due to cognitive decline would enter the private rooms of other residents. To restrain the residents who wandered would be a severe concern for autonomy and quality of life, but without the restriction of wandering other residents suffered. When asked how this issue was addressed, the nurse responded that it was “on the fly” and that this was just one of the “day-to-day issues” they had to deal with.

Conflict between residents was seen first hand during participant observations. A resident who had a history of obsessive compulsive disorder was also suffering from later stage dementia. He had a son who visited him daily at lunch time, but the resident was otherwise quite demanding, relative to other residents, on nurses’ time. One of the resident’s behavioural issues was that he would panic when left alone if he was not asleep. During meals he needed to be told what next to put in his mouth with every bite. When attended to, the resident was generally calm, but would become very vocal when left on his own for even a minute. One of the field observation participants reflected that many of the residents were quite fond and even protective of the unit staff. There was a concern that a couple of the more independent residents might “do something” to this

particular individual. The participant said that the other residents had been assured on several occasions that the behaviour of this one resident was not too demanding of them and were told to leave him alone. Still, several of the residents were seen glaring at him during observations and he seemed to be afraid of them.

One of the field observation participants noted that there had been a suggestion made to move this resident to a psycho-geriatric floor where he could receive more specialized care. This suggestion was made both due the conflict on the floor and the fact that psycho-geriatric floors had a better staff-to-resident ratio to help deal with challenging behaviours. However, it was explained that unit staff thought the resident had only a couple of months left to live and due to his combination of obsessive compulsive disorder and later stage dementia it was felt that a move to a psycho-geriatric floor would be a greater detriment to his quality of life in his last months than would be leaving him on the unit where conflict was an issue. They also felt the move would cause a more rapid decline. The decision was made to keep him in a consistent environment with the care providers he knew.

Conflict was also discussed by participants as it occurred between residents and members of their families. Intra-family conflict was explained in two ways. The first was conflict resulting from long-term family dynamics and the second type of conflict resulted from disagreement over care options. Key informants expressed feelings of helplessness over the first type of conflict as this was discord that started long before the care providers entered into this group dynamic. It was felt that in many cases there was nothing that could be done to resolve these kinds of issues during the relatively short period of time that they were involved in care. One frontline worker relayed the situation

of one resident that she cared for,

He wasn't able to breathe, he was on oxygen and he was in a lot of discomfort, but he was estranged from one of his daughters and I think he was waiting for her to come to see him and we did everything possible to locate her and being able to bring her in so he could talk to her. And we were not able to convince her to come... I remember he had everybody at his bedside, his sister came, his niece came, his other two daughters and he was not able to let go, he was just waiting for her. So finally, we said "you know what it's okay to let go..." his whole body just went... it was finally, he got permission to go.

Conflict resulting from disagreement between family members and the resident was consistently voiced as a challenge to providing the best possible quality of life. One nurse expressed that meeting the needs of both resident and family was a challenge particularly when their end-of-life goals were different, because it was impossible to grant the wishes of everyone involved. This was illustrated very well by one nurse educator when she was asked to define her use of the term "problematic family".

A family that probably doesn't go in the same direction as the staff... in the sense of the level of care. That's usually where the problem exists. They will want us to continue everything... And the staff will say we think it would be better to turn to a comfort care and there's the dichotomy... Or there's the overwhelming spouse... that will never leave and that will be so anxious, be overbearing trying to [feed] them when they can't swallow... too overwhelming... we see the patient sort of telling us by eyes you know "Get her out of here. I'm going crazy. I want to rest." So, that's what I mean by problematic... we sense that it's not for the patient's well-being and that we're not on the same ground.

Key informants were questioned about how they handle conflict over treatment options between individual family members and between the resident and his or her family. The consistent response was that it was necessary to respect the autonomy of the resident if he was competent enough to make care decisions. Several key informants pointed out that even if a resident was not competent enough to handle his or her own money, they may still have the cognitive ability to participate in health care decision

making and planning. One frontline worker stated,

If it's a resident who can make his own decisions and he can verbalize what he wants, then obviously he will be our very first [priority]... whatever his wishes are... If he wants certain things and the family disagree, we would go with what he wants.

The situation could become less clear when the resident was unable to make decisions on his own. In some cases, conflict could occur between between staff and family members over how to proceed with treatment. Many key informants felt that they developed caring relationships with their residents over time and, as a result, had a good handle on how each of the residents would want care to proceed. However, if the resident was not able to express their end-of-life wishes staff members had to defer to the family for decision making.

Several interview participants found it was a challenge not to vocalize their opinions when families were making decisions about treatment and care. In some cases, key informants felt these disagreements could be solved through education of family members. For example, families could be educated about how tube feeding, IV medications, and other such treatments would affect the resident and about how the disease would progress given the various treatment options.

Key informants also discussed the resident's right to know about their health status. It was explained that sometimes family members might request that the resident not be told about their diagnosis and prognosis feeling that this information would be too difficult for the resident to handle emotionally. When asked how they addressed this issue, there did not seem to be an easy answer. One key informant discussed giving the family time to accept the information before discussing it with the resident. Another said that she informs the family about the resident's right to know and then helps the family

discuss the situation with the resident. Finally, a nurse manager discussed the emotional costs of keeping the truth from a resident in her care.

We do a lot of education with folks about the resident's right to know about their own condition... And what impact that may have on the resident and the impact that has on staff of we're asking them to keep secrets... And how that might in fact infringe on their relationship.

Key informants also discussed conflict between team members. Most often the conflict seemed hierarchical in nature with the nurses not agreeing with the decisions made by the physicians involved, but lacking a means by which to address the disagreement.

We have an ethics committee. The problem with the ethics committee which I find it has that it has to be... if we want to consult them it has to go through the doctor but often there's a problem between the nurse and the doctor... I can't even go to the ethics committee to ask them help because he has to approve it and he doesn't want to.

Nurses have expressed a frustration with regards to physicians disregarding their judgment and recommendations (Ersek, Kraybill, & Hansberry, 1999). As to the nature of the conflicts occurring between nurse and doctors, another nurse described her perspective on physicians.

Talking about the future, you know, the sickness, the dying part... Like they weren't born to make people die. They were born to make them alive... And end-of-life sometimes I feel is not their best [strength]... We're fighting sometimes with the doctor to make sure they do talk to the family or that they do relieve the pain, because- and they say, "Well, it's gonna kill him." I'm sorry- so what? He's going to die [anyway]... I mean we're not going to make him die. We're just going to treat him.

It should be noted that this type of conflict was mentioned in concert with discussion about how well the nurses and doctors are often able to work together to ensure high quality care. However, when this conflict did arise it was felt that it was to the detriment

of the resident's quality of life.

Implications of interpersonal interactions. Care conferences, detailed progress notes, briefings at the beginning of every shift, and ongoing communication were all found to be enhancers to quality hospice palliative care. Regular care conferences can help to ensure the resident's and family's wishes for end-of-life care are addressed before a health crisis makes the decision-making process more emotionally challenging. Based on the data collected it is best to hold care conferences at regular intervals during the resident's stay. Policy makers should be providing guidelines for ensuring that staff are communicating with residents on an ongoing basis about their needs. This should include providing standard timelines for bringing the entire care team together for care conferences on each individual resident. Each care conference should review the end-of-life care wishes of the resident in case wants and needs have changed. Policy guidelines should also ensure family meetings are facilitated with all necessary specialists whenever there is an acute change in the resident's health condition. This helps to facilitate the decision making process at the end of the resident's life and provides that the best possible treatment options are decided upon by the resident and his or her family.

Informal conversations between unit care providers and residents enhance care received by allowing care providers an opportunity to ask questions in an environment that may be perceived to be less stressful or threatening than a care meeting or a doctor's appointment. Care providers may be able to gain further information about the residents' needs and wishes through asking simple questions about their daily lives, activities, and how they feel physically and emotionally. Care providers may then suggest appropriate changes to the care plan based on information received. Informal conversations also

enhance quality of life through ensuring that the resident has some social interaction with staff. This ensures the resident knows that staff care about their well-being. This can provide some emotional and social support to residents. A common challenge to informal conversations is individual comfort level with discussing death and dying with residents. Leaders in hospice palliative care within the facility need to find ways to work with frontline care workers and encourage them to enter into these conversations and to help them feel more comfortable.

A challenge to all of the above methods of communication is time. Some key informants expressed feeling stretched thin with their time. They may find it difficult to use all of the above methods of communication on a daily basis. The obvious solution to this is additional human resources, but this requires additional funding that may not be available. Unit managers should stress the importance of ongoing communication as a means of ensuring that the holistic needs of residents are understood and met. A prioritization of communication among unit staff would facilitate working communication into their daily tasks and potentially improve quality of life of residents.

Ongoing communication with residents is further facilitated through lengthy stays relative to acute care facilities. Staff have longer periods of time to gain an understanding each individual resident and develop relationships with them. In many respects the relationships formed between care providers and care receivers in the long-term care setting act as an enhancer to quality hospice palliative care service delivery. Care providers have an opportunity to get to know the resident, really understand their needs, and explore their needs further. The time available to form relationships also affords them the ability to come up with care plans that are as individualized as possible. Because each

care receiver is known well by the staff, care providers are also alerted quickly to small changes in condition. This allows them to quickly address issues as they arise.

On the other hand the relationships formed between staff and residents can be a barrier to quality care, because there is an emotional toll paid by the care providers when a resident dies. Several key informants expressed feeling like part of each resident's family. Based on the data collected, these relationships should be encouraged as they significantly contribute to the improved social, emotional, and physical care of residents. However, there is a need to ensure the staff giving care receives the emotional support necessary to continue in their roles. This will be discussed further in subsequent sections.

Despite the fact that relationships can foster positive care environment for residents, interpersonal interactions can also lead to conflict on many levels. Whether conflict is derived from disagreement over decision-making, dissemination of health status information, or long-term family dynamics it is typically a barrier to quality hospice palliative care service delivery. Based on the data collected, when disagreements arise the needs of at least one party are often neglected. Focus can be drawn away from the needs of the resident or the family depending on the type of conflict that exists and leave unit staff feeling helpless. Due to the emotional aspects of death and dying as well as family dynamics, it is unlikely that there is a universal solution to conflict. Data collected uncovered little as far as guidelines for handling these stressful situations.

Although it is recognized that some conflict situations truly need to be handled on an individual basis, such as the case of wandering residents suffering from dementia, clear guidelines for addressing conflict that is commonly experienced need to be developed to assist frontline workers in dealing with these stressful situations. For

example, one written policy did refer to standard procedures to follow when the family or resident were unhappy with the care provided by or decisions made by the physician involved. However, at another facility, the solution put in place to address disagreement with the decisions made by a physician was an ethics committee that required a referral by a physician. Key informants felt that this was a direct conflict of interest and was ineffective. With respect to conflict within the family, some key informants referred to the availability of physicians, psychologists, social workers and pastoral care workers in assisting with conflict resolution and mediation.

With reference to conflict resolution, the CHPCA model states that, “A process [should be] used to resolve conflict that is acceptable to the [resident], family, and [care providers]” (Ferris et al., 2002, p. 32). The model does not expand further on this area of hospice palliative care service delivery in any care setting. Further research is needed to understand common experiences of conflict inside the scope of hospice palliative care service delivery in the long-term care setting and to develop guidelines for mediating such conflict while maintaining an individual approach to each situation.

Resident-focused care

The first research question of this study attempted to determine what program components were necessary to deliver quality hospice palliative care. The written palliative care policies received provide the framework for meeting the holistic needs of the residents through providing these required components of care. However, it is the application of these components into practice that ensures that resident needs are actually met. It could be possible to provide a variety of services such as physical care, psychological care and social support without respecting the wants or needs of those

being treated. The participants in this study all described actions taken to ensure that care provided was resident-focused.

Assessment and continuity of care. Previous sections have discussed primary care assignments, open communication, and relationships as enhancers to providing quality care. One of the many reasons that these things enhance care is because they facilitate continuity of care. Key informants reflected that continuity of care was further facilitated through regular nursing assignments and ongoing nursing assessments. Several nurses indicated that at their facilities nurses were often assigned to the same residents for a specified amount of time, allowing these residents to become accustomed to a certain level of routine with their care providers. This amount of time varied by facility, but all participants believed that regular nursing assignments allowed them to know the residents' care plans well and to be able to identify when changes to the care plan should be discussed.

Some key informants felt that they often knew the residents so well that through daily interaction they were able to detect many issues as they arose. They also had at their disposal the use of ongoing nursing assessments to help identify health concerns and changes in health status. It is important that unit nurses in long-term care are able to do accurate pain assessments and be able to communicate these assessments readily to physicians (Winn & Dentino, 2004a). An inability to properly assess residents can result in missed opportunities for care planning, inappropriate treatment decisions, and unnecessary transfers to hospital (Wetle et al., 2005). The key informants discussed several different assessment tools for various health conditions, including pain assessments and mini-mental status examinations. The tools discussed were all validated

measures of health status according to the management level participants interviewed. While certain health care professionals, such as pastoral care workers and geriatricians, made regular visits to nursing units, these assessments helped frontline workers to identify when residents needed more dedicated attention from these professionals and when other specialists should be brought in for consultation. However, it was noted by three key informants that dementia presented a specific challenge when assessing residents for pain. While acknowledging that validated assessments tools were currently available, one of the key informants saw pain assessment in residents with dementia as a barrier to quality of life and felt that much research was needed in this area to ensure that all residents were appropriately treated for pain.

Response to cultural diversity. According to key informants the vast majority of residents at the participating facilities were male, Caucasian, Christian, and either French or English speaking. This was not surprising as the facilities studied were dedicated in whole or in part to the care of Canada's war Veterans. However, it is important to respect and respond to cultural and spiritual needs to assure the highest possible quality of life for residents from diverse backgrounds (Brazil et al., 2004). Key informants did speak of residents who came from other cultural or religious backgrounds and how these individual needs were met.

Open communication was discussed in a previous section to be an enhancer to quality hospice palliative care. Key informants indicated that although most residents were English or French speaking there were some resident who spoke other languages. One nurse pointed out that even when these residents have learned English they could sometimes lose some of their ability to speak or understand it when declining cognitively.

These residents may retain a firmer grasp on their mother tongue. When asked if there were translating services available to ensure that these residents are able to communicate particularly during care conferences, key informants indicated that this was not generally available. However, a common solution to this challenge was discussed by key informants from three of the five participating facilities. This solution was a list of staff members who were fluent in languages other than the language spoken predominantly at the facility. These staff members could be called in as needed to ensure that the resident and the family completely understood the necessary information to make care decisions. Assigning these staff members to individual residents did not always seem to be an option on an ongoing basis, but the language skills of these individuals was a valuable tool to enable staff to make communication at important times resident-focused.

Ensuring that religious rituals were respected during the dying process and after death could also be a challenge as residents and staff at participating facilities were predominantly of the Christian faith. Key informants discussed looking to spiritual care workers and family members to guide them in meeting individual religious needs. For example, several key informants indicated the availability of rabbis to assist with Jewish residents. At one facility a rabbi visited every Monday to provide spiritual guidance to residents who desired this type of care. This rabbi was also available to inform and guide staff regarding actions necessary to ensure religious needs of residents were met at the end-of-life. When specialized care like this was not available, key informants indicated that staff looked to family to ensure that the cultural and religious needs of the resident were met.

Key informants reflected that some cultural strife could exist within the facility

and that this could be a barrier to quality care. One frontline worker pointed out that it is important to recognize that the resident population in this study fought in a war against specific nations and may still carry with them strong feelings about this experience.

Although most of the Veterans living at the participating facilities were Canadian, in some cases the Veterans were from different countries and this could be a challenge to ensuring each individual resident received culturally sensitive care. One person said,

We have one fellow who is Japanese and we have one fellow who is German. And the only reason that I mention him [is that]... he was a Veteran as well, but a Veteran of the German Army... But, he was married to a Canadian Veteran. There was a lot of dissention and fear when he first came... because he was the enemy... [now] enough of the population has turned over that some of them don't know that... So, I would say that the discrimination towards him has certainly abated.

The challenge here was to be culturally sensitive to all involved. On one side there is the cultural strife created by the experience of war that is specific to the many Canadian War Veterans who are residents at the participating facilities. On the other side there is a need to provide a safe, secure environment free of discrimination to individuals who sixty years ago literally were the enemy and may still be considered to be the enemy by some of the residents.

Sensitivity to need. There are several components of hospice palliative care that are written into policy and are applied into practice on a daily basis that make the care received resident-focused. Some of these components have already been discussed. These include a focus on holistic care, timely access to specialized care, modified care allowing the resident to transition from curative care to comfort care as they desire, and respect for the autonomy of the resident when making care decisions. All of these components can be verbalized as required components of daily practice. In addition, it is of utmost

importance from the perspective of the family that residents be treated with sensitivity and dignity (Vohra et al., 2004). Care providers can foster respect and dignity during dying (Brazil et al., 2004) by being sensitive to the individual needs of residents. The actions required to make care sensitive are less tangible than specific services and timelines for care received. Yet, they are not easily written into standards for care delivery.

During key informant interviews it became apparent frontline workers took action on a daily basis to improve the quality of life of residents in their care. These actions illustrated the caring role of the frontline workers and are best expressed through the words of the key informants as they told stories of caring for the dying. One nurse spoke of the importance of being sensitive even when the resident does not seem cognizant of his or her surroundings.

There was a nurse who told me that... [she] was taking the pulse of a semi-comatose patient and [she] whispered to one of the daughters. The second daughter came in while [she] was taking the pulse and she started talking to the other daughter about what they would do for the burial... She said [she] was still holding the patient's [arm]... doing his pulse and it went from 72 to 100... they hear everything... so she says [she] told them could we please discuss that [outside].

Another nurse felt that knowing the resident's interests could help improve quality of life and death.

We had a resident and this gentleman was a very avid hockey fan... And the year when Canada went to the world championship and they won the gold medal, our gentleman was... dying... for some reason we had a staff [member] who didn't know him very well... They put on classical music and I remember I came to work on the evening shift and I guess we didn't have it written anywhere that he did not want music... and, by this time... was in a coma... so, I gently turned it off and I put on a hockey game for him. I don't know if he was able to hear it or not, but I just presumed he did. And, I stayed with him and I was holding his hand and he was just like very comfortable, very quiet... very at peace... It was actually like a replay of the hockey game when we won the gold

medal. It was the last game and when Canada finally scored the winning goal, that's when he passed away... that's why I'm stressing it's very important to know the individuals because if you don't, we would not be able to provide care.

A nurse manager reflected that staff could at times surprise her with their sensitivity. She told of coming by the room of a dying a resident and finding him alone. Frustrated she turned to go look for the assigned nurse and found her coming back to the room with flowers she had picked to make the décor a bit more warm and inviting. Another manager spoke of how flexibility within the team could make resident quality of life better.

When a person is heading towards their end stages of life the staff really step up. And they make sure they're comfortable and they make sure that everything they could possible need or want is there... we had a fellow... who wanted some chocolate pudding... he'd been semi-comatose for a few days and kind of had a day that he was brighter and we asked him what he would like. And he wanted chocolate pudding. So, we went downstairs and the kitchen didn't have any chocolate pudding made up, but the manager went out and bought some of those jello cup chocolate puddings. And thinking that this was going to be very important to him she bought... a whole flat of them... The next day... he wanted vanilla pudding... and it was the weekend. And the kitchen, "Well, we've got chocolate..." No, that was yesterday. Today he wants vanilla. Well there's- like what do we do now?... And the cook, bless his heart, made a custard for him.

Program evaluation. One of the limitations of this study is that the data collected is gleaned only from workers in the field. Although the data was collected from two different standpoints, management level and front-line workers, the perspectives of the families or the residents were not gained. However, the key informants, particularly at the management level, had an understanding that if care was to be resident-focused, the hospice palliative care programs had to be evaluated and revised utilizing resident and family input.

At the time of the study, three of the five facilities were in the process of revising their hospice palliative care policies based on program evaluations in the interest of better

meeting the holistic needs of residents and their families. At one facility, a pilot project had been put in place on one unit to implement and evaluate the changes made to the hospice palliative care policy at the facility. At another facility, one key informant explained that the palliative care team at the facility also asked for continual feedback from unit staff so they could evaluate themselves and make changes as necessary. Key informants from three of the facilities discussed quality assurance programs and quality indicators that were put in place to ensure that hospice palliative care standards were being met throughout the facility. These were in place regardless of whether or not changes were being made to the policies or programs at the facilities.

Implications of resident-focused care. The average resident length of stay is an enhancer to quality care because longer stays allow staff the opportunity to get to know the resident and their care plans well. This improves continuity of care and makes staff more alert to the changing needs of the residents in their care. Based on the data collected, staff awareness of residents needs is further facilitated through regular nursing assignments. Therefore, it is recommended that whenever possible nursing staff be assigned to a small enough resident population that they are allowed the opportunity to become well acquainted with each individual resident.

When asked to compare their own facilities to other facilities in their region, key informants often pointed out that at their facilities the bulk of daily care was carried out by licensed practical nurses and registered nurses. In contrast, other facilities often utilized personal care workers for daily care and nurses filled management roles. It was felt that the skill sets available at the participating facilities was superior. One of the many things that these skills afforded was training in the application of validated nursing

assessments. The availability and application of these assessments on an ongoing basis was an enhancer to quality care as it alerted unit staff to possible changes in health status of individual residents and to follow up with relevant specialists regarding treatment. According to these findings, front-line care workers should have skill sets that include training in ongoing nursing assessments.

Even with the above training several key informants expressed their concern that a lack of effective measures for pain and symptom assessment in residents with dementia was a barrier to quality care for these residents. Although some validated assessment tools are currently available, there was a consensus that residents with dementia are often under-treated for pain, because these assessments are not effective enough. Further research is needed to develop better tools for assessing pain and symptoms in individuals diagnosed with dementia.

Although frontline staff in this study had a diverse skill set, language and culture still presented unique challenges. Even with dedicated funding for hospice palliative care programs, translating services were not readily available at the participating facilities. In addition, unit staff seemed to look to families for guidance when carrying out cultural and religious rituals at the end-of-life that are not specific to Judeo-Christian faiths. It was apparent that unit care teams and hospice palliative care teams make effective use of those resources available to them to ensure that the individual cultural and religious needs of dying residents are attended, but gaps in service still existed.

It is recommended that policy makers implement standards to ensure that specialists in spiritual care receive training in the rituals of as many minority backgrounds as possible. This may enable them to the assist unit staff in understanding

required rituals at the end-of-life and in developing care plans that are respectful of diverse cultural needs. Policy makers may also look to the community surrounding the facility to collaborate with cultural and religious groups who may assist unit staff in the same endeavours. In addition, the funding of translation services for key meetings, such as care conference, may help to ensure that residents and families are able to make care decisions fully understanding health status, prognosis, and the available treatment options.

There are a wide range of individual needs, including cultural and spiritual needs, that makes each resident unique. This uniqueness requires the sensitivity and observance of staff if individual needs are going to be met. As already mentioned, it is difficult to write individual actions that occur in direct response to need into an overarching policy directing service delivery. However, caring attitudes that respect dignity and individuality in death and dying are certainly an enhancer to quality hospice palliative care. It is important that leaders within the facility recognize, encourage and support these attitudes in unit teams. Fostering these attitudes can be done through a variety of methods including debriefing at team meetings, employee recognition programs, and continuing education. Unit managers should be looking to hire unit staff that display sensitivity to need and coach staff when attitudes become less than sensitive and caring.

Hospice palliative care programs and the staff delivering these programs need to be evaluated periodically to ensure they maintain a focus on the resident. There is recognition by facility management that the existing hospice palliative care programs need to be evaluated on an ongoing basis. These program evaluations enhance quality of care received by allowing facilities to further develop their hospice palliative care

programs in order to better meet the holistic needs of dying residents. Based on the data collected, programs are primarily evaluated based on the input of the staff who are delivering the hospice palliative care services. Although unit staff have valuable experience and should continue to be consulted, they are limited by perspective. Attaining input from the perspective of users of the programs, such as residents and family, could serve to further develop high quality programming. Policy makers need to develop programs evaluations that allow residents and families to provide input while being sensitive to emotional readiness to participate in such an evaluation.

Family Support

Key informants describe the long-term care setting as unique for a variety of reasons, including the fact that many residents are cared for by the staff for a long period of time before they are faced with life threatening illness. During this period of care, family and friends can be seen as members of the care team. Although they do not contribute to physical care on a large scale, key informants discussed how many family members help with activities of daily living such as grooming and feeding. They may also play a role in the social well-being of the resident through visitation and social activities. The roles that family and friends play within the facility change when the resident is diagnosed with a life threatening condition. In many ways they may still contribute to the care of the resident, but they also become care receivers in that they required physical, emotional, social, and spiritual support from the care team during the health crisis of the resident and beyond. Areas of family support that emerged from the data collected included accommodation, decision-making, emotional support, and bereavement care.

Accommodations. In recognizing the family as part of the unit of care along with the resident the importance of providing for the needs of the family must also be recognized (Brazil et al., 2004). Although families do not require physical care in the way that residents do, they often require support in ensuring they are able to be with the resident during his or her final days. It is important that being with the resident is made convenient for the family (Brazil et al., 2004). All of the participating facilities provided some type of accommodations to family and friends when needed. The provision of this physical space contributed to the social and emotional care of the resident's loved ones.

The type of accommodations available to family and friends was dependent upon the physical resources of the individual facility. For example, at one facility actively dying residents were transferred into palliative care rooms. Each of these rooms had a pull-out sofa to accommodate anyone who wished to remain with the resident overnight. Another facility provided onsite rooms at low or no cost so that loved ones could be in close proximity to the resident at all times during the health crisis.

Although each of the facilities made some type of physical space available to friends and family, at high volume times when several residents were actively dying this physical resource could become strained. During these periods, unit staff used flexibility and creativity to meet the needs of loved ones.

Once my patient was going so bad... I said to the family, "We'll move him into the living room."... We transferred everything into the living [room] and that was his room... I think within three days he went... And the family could sleep over. There was a sofa and a bed. They opened it. They slept there. We offered quality care.

This flexibility illustrated the importance placed upon support for the family by facility staff.

Decision-making and emotional support. Key informants expressed that during health crises decisions about treatment often need to be made very quickly. Whenever possible, the resident he or she can make these decisions as needed. However, key informants indicated that more often due to either cognitive decline or a comatose state, the care team must defer to the family for these decisions to be made. Family member need assistance in the decision-making process and support in the decisions (Brazil et al., 2004) as decisions made on behalf of loved ones can be accompanied by feelings of guilt and burden (Forbes et al., 2000). It was up to the care team to ensure that family members were properly informed and emotionally supported during this process.

When asked, unit staff and management level key informants felt that generally family members were given all the information necessary to make informed health care decisions on behalf of residents. It was acknowledged by several key informants that they often lacked the time to have in-depth discussions with family members when formal care meetings were not scheduled, but they said they “make the time”. One front-line worker stated that she had often let family members know that she would sit down with them at the end of her shift, so that they could have her undivided attention. However, this was the perspective of the staff and was without input from families or residents. A study of family perspectives on hospice palliative care service delivery gave low ratings to family support including, “updating family on the status of the [resident], and involvement in care planning and decision-making” (Vohra et al., 2004, p. 301). It should be noted that the facilities in this study may not have had the level of staffing available at VAC facilities. Still, the family perspective would need to be studied to determine if they are getting the information necessary to make informed decisions.

As previously discussed, one of the ways in which the care team facilitated open communication was through care conferences with each resident at regular time intervals. With the permission of the resident, family members were included in these care conferences. This allowed that family members were kept apprised of the end-of-life care wishes of the resident. Some key informants believed that this could relieve some of the emotional burden associated with making treatment decisions on behalf of a loved one. Key informants felt that including the family in these sessions and allowing them to be a part of the decision making process well before a crisis occurred enabled them to make more rational decisions that better reflected the wants and needs of the resident when the time came to do so.

However, several key informants relayed situations in which they encountered family members who were not ready to “let go” and wanted everything possible to be done for the resident even if this went against his or her wishes. In other cases, family members arrived only during the health crisis and had not been involved in previous care planning meetings. These family members came into the situation without the information necessary to make educated decisions on behalf of the resident.

If it goes fast... like the health status [quickly deteriorates] then, the family, it's hard for them to cope with the sickness. Usually, I try to come... to talk about what they think if he ever gets sick, before... [he gets sick]. So, it does prevent them [from] asking the questions when they are in an emotional state... And I implement [with] the patient and family, so they hear what the patient wants when he's up and all right. So, when the crisis happens it's easier to ask, “Do you remember what he wanted?”

There were also family members who were conflicted all along about the decisions of the resident and wanted to change the treatment options once the resident fell into a comatose state. Front-line workers were asked how they cope with these situations.

In many cases, key informants responded that when the resident was cognitively able to make their own decisions their first concern was the resident and they did not consider the wishes of the family. This response was understandable, because it respects the autonomy of the resident. However, of particular concern was that none of the key informants who responded in this way identified ways in which the family was emotionally supported when the resident's decisions went against their own wishes. This may indicate that there is a gap in service with respect to emotional care for the family. This finding is consistent with the results of another Canadian study in which family members surveyed gave low ratings to family support received by long-term care facilities (Vohra et al., 2004).

Key informants also discussed cases in which the decisions of family members went against what was known to be the wishes of the resident before he or she fell into a comatose state. When asked how they coped with these situations, key informants indicated that often giving the family some time to come to terms with what was happening or educating them further about the disease progression allowed them to come around to deciding on what in the best interest of the resident. There was acknowledgement that in some cases this type of conflict simply could not be resolved and that eventually the body of the resident would give up and the time for decisions regarding end-of-life care would be over. One participant during field observations told a very emotional story about the wife of one Veteran who fought a very long battle with his illness. Several hours after his death this nurse was helping this very frail woman down the hallway. The woman repeatedly yelled at the nurse that they had "finally killed her husband". The grief felt by the nurse even several months after the incident was still

apparent, but she said she simply continued to help the woman down the hall as there was nothing else she felt she could do.

Aside from being supported in the decision making process, family members and friends also need emotional support during the resident's disease progression and during the final stages of life. For example, educating families on what they will see when their loved one is actively dying can support them emotionally. This may serve to decrease their anxiety and distress through an understanding that the physiological changes they witness are normal and do not cause the resident any increased discomfort (Brazil et al., 2004). Key informants indicate that there are social workers, pastoral care workers, and psychologists that can be consulted as needed, but did not expand on the specific roles of these individuals on the care team with respect to the family. In addition, during participant observations several posters were noted around the facility that advertised support groups for family caregivers. When asked about the specific strengths and weaknesses of the palliative care programs, several key informants indicated that emotional support for family members was an ongoing challenge, but was also an area that they felt had been improved in recent years.

As with resident-focused care, many of the actions taken by front line workers to provide emotional support to family members were undertaken in response to individual need. They were solutions that seemed to come out of the flexibility and ingenuity of the care team. One example was given of a woman who had both a spouse and a mother living in the same facility.

[We had a resident who] was 108... when she passed away a few weeks ago... her son-in-law on the other wing... was in his late 80s... now they didn't get along that well together. So, they were on the same floor, but they were on different wings... And, the primary caretaker for both of them was his wife, her

daughter. So, she was able to come and visit them with ease. She was only going to one place.

In this example, providing appropriate accommodations that were also convenient eased the level of stress experienced by the caregiver when she visited her two family members who were residents. In another example, a front-line worker explained how it is necessary to support family members who feel isolated even though so many people are going through similar experiences at the same facility.

[One resident] was a... professor and was head of a [research institute] for a long time... He had Parkinson's and he... basically came in to die with pneumonia... his wife was able to have a van and he'd go home for Sunday dinner... she could only handle so much of it. You know she couldn't handle incontinence... and a lot of choking incidents at the end... But, I always thought he had a good quality of life... I know his wife felt she [was] separate from a lot of people... She found dementia hard to [handle], very hard to deal with... and [the] loss of dignity... she made choices not to pursue intravenous antibiotics... That was a very intellectual process that she went through. So, maybe a much heavier burden for her... She saw this man go from... being the head of [a research institute] to being... a cripple with dementia in a wheel chair.

Several of the key informants expressed their opinion that one difference between hospice palliative care in acute care versus long-term care was that in long-term care unit staff often had the opportunity to get to know and develop relationships with the family members of residents. It was felt that these relationships better enabled them to support the family emotionally during the end stages of a resident's life. However, it was also felt by some that the provision of this emotional support to family was an ongoing challenge and an area in which they were weaker when compared to the physical, emotional, and social care provided to the residents themselves.

Bereavement care. One of the areas of care and support for the family that appeared to be absent at some of the participating facilities was bereavement care. Key

informants explained a variety of ways in which families were supported following the death of a resident, but for the most part these methods were informal in comparison to components of a dedicated bereavement care program. This was not true of all facilities. For example, at one facility a structured bereavement care programs included contacts with the resident's family members at specified times following the resident's death by a variety of methods including a one-year sympathy card letting the family know they have not been forgotten on the first anniversary of the resident's death. A key informant from this facility explained that the feedback received on the service had been very positive and the bereavement program was constantly evolving based on program evaluations.

Key informants from another facility indicated that they were in the process of developing their own bereavement care services based on the program available at other facilities. Less formal methods of offering the family support following the death of a resident included sending sympathy cards signed by all members of the unit staff and inviting family members to memorial services held at regular intervals at the facilities. At some facilities, unit staff were encouraged to attend the private funerals of residents to offer support to the family and to participate in their own grieving process.

Implications of family support. The provision of accommodations to family members during a health crisis or the final stage of a resident's life is an enhancer to quality hospice palliative care service delivery. Even though the provision of space is a type of physical care for the family, it is also an emotional support as it prevents additional stress created by traveling to and from the facility to visit with the resident. Loved ones are afforded the opportunity to be with the resident at the time of his or her death if they so desire. Key informants believed that family members should be allowed

to stay with or close by the resident at the end-of-life and that unit staff should use flexibility and creativity to ensure this happens when physical space is limited. Policy makers should ensure that facility guidelines for hospice palliative care include accommodations for family members at low or no cost when a resident is actively dying or facing a health crisis.

Aside from the provision of accommodations to family, there appears to be a gap in service concerning emotional support to the family. Stretched thin for time, key informants felt they did their best to ensure that family members had all the information necessary to make decisions on behalf of dying residents. Still, several key informants discussed emotional support of the family as an ongoing challenge and there appeared to be a consensus between all key informants that the primary focus of care should be the dying resident. This is understandable as the health crisis of the resident is the primary reason for the entire treatment plan.

Should conflict arise between the needs of the resident and the needs of the family, key informants indicated that their main concern was the resident. There was some discussion about individual methods of supporting the family during this conflict, such as further educating the family on the health status and prognosis of the resident and allowing them some additional time to accept the situation. However, there did not seem to be a consensus solution. This complete focus on the resident may be a barrier to quality hospice palliative care with regards to the family. As facilities continue to develop their hospice palliative care programs, policy makers should look for ways to improve emotional support for family members without diminishing the level of care offered to the resident.

When applying the CHPCA model to the participating facilities, bereavement care is a notable gap in services at most facilities studied. The lack of bereavement care services is a barrier to quality hospice palliative care service delivery. According to key informants, there is little follow-up with family members following the death of a resident by representatives of the facility. Without such a follow-up, facility staff have no way of knowing if the grief support needs of family members are being met nor are they contributing to the emotional support of the family following the death of the resident. As facilities continue to develop their hospice palliative care programs, bereavement care is an area that should be considered for development. It is recommended that policy makers look to the community to find grief support groups and other types of counseling to which they may refer family members if they do not have the resources to provide in-house grief support or bereavement care.

Staff Support

The majority of this study is being analyzed using the *Square of Care* section of the CHPCA model. There is a component of the *Square of Organization* section of the CHPCA model that touches on supporting staff both emotionally and in their everyday care work roles (Ferris et al., 2002). It was felt by several of the key informants that the informal and formal supports they received in the workplace had a direct impact on their abilities to provide quality care to residents and families. Although it is not included in the *Square of Care*, staff support may be seen as a direct enhancer of quality hospice palliative care in the long-term care setting.

Education and skills. Winn and Dentino (2004b) reported that because many families are now choosing to have their loved ones remain in place rather than be

transferred from long-term care to acute care, physicians and long-term care staff need to develop skills, knowledge and attitudes consistent with the philosophies of hospice palliative care. The CHPCA model states that all hospice palliative care service delivery should be knowledge-based (Ferris et al., 2002). According to key informant interviews, one of the best ways that front-line workers were supported in their roles caring for the dying was through ongoing educational opportunities and skills training.

Several key informants discussed opportunities to go to conferences to gain education on more innovative and progressive treatments in end-of-life care. These conferences could be collaborations between local long-term care facilities to share knowledge or they could be provincial or national level conferences aimed at disseminating new empirical knowledge. In some cases, key informants indicated that only key representatives from the facilities had the opportunity to go to these higher level conferences. However, the knowledge gained by these individuals was often passed along to other facility staff through in-service education sessions. More opportunities were offered to unit staff to go to local continuing education events. One example of this was a three-day hospice palliative care education program for front-line workers organized and facilitated by the provincial Cancer association.

In addition to conference and local education sessions, key informants discussed skills-training that was often available to unit staff. Most of this training was directed at the physical care of the resident. Examples provided include refreshers on dialysis, wound management, and pain and symptom control. However, sometimes these sessions were directed at providing front-line workers with personal skills that enabled them to carry on in their roles. For example, one nurse mentioned a stress program that was well

attended. To ensure that the educational needs of staff are met several of the facilities have either a hospice palliative care coordinator or a committee whose responsibilities include hospice palliative care education for all unit staff members.

Informal and formal supports. When asked, all key informants stated that they felt supported in their daily caring roles. Key informants were asked how facility management ensured that unit staff were supported both professionally and emotionally. The responses were wide ranging and included both informal and formal coping strategies and support networks.

Each of the individual key informants seemed to have their own methods of coping with the daily demands of caring for the dying. One front-line worker discussed having “good team spirit” within the unit that allowed them to support each other.

Another spoke of being able to turn to colleagues for support,

I have very good colleagues and some of them [I am closer to] than the others. But, you know personally I would not hesitate to go up to somebody and say look I just need to let go and I would cry. And I know it’s okay with the other person... she’s not going to judge me.

Several front-line workers also expressed feeling comfortable turning to their supervisors when needed,

The unit manager I have right now, I have never seen her say “no” if we needed her for anything. Like if you need to discuss something and we are desperate... or not even desperate, just to run something by her. She wants to know and she would make time even if she has a meeting... she will say, “I can only stay 10 minutes... but I will come.” And so we know we can rely on her in this way.

More formal supports include the roles of specialists that supplement the skills of front-line workers, team meetings, and employee assistance programs. Specialists such as palliative care coordinators, and pastoral care workers support the caring role of unit nurses complimenting the care provided by unit staff. Unit staff members were able to

consult out to a variety of specialists both for advice in their own role and to help deliver care. Although these specialists are available on an ongoing basis, at least one management level key informant felt they could be doing more to support unit staff,

I think the committee has to be a little more present on the floors... I think that's [probably going to be] our next objective this year or next year. To be more available because it's only through talking about the patients... being able to have sessions where we let the staff vent... that we're going to [know] their frustrations and be able to work on them.

Team meetings and debriefings are one method by which nurse managers and palliative care coordinators bring unit staff together to discuss issues and problem solve.

One of the management level key informants had this to say about these meetings,

I do a session... end-of-life sort of very informal once a month that all staff from all units can come to, to kind of debrief what's transpired over the last week, what was difficult or what's common. And I think bringing those people together collectively [helps]... sometimes nurses may feel they work in isolation and they're the only ones that feel a particular way. But, I think the conversations that occur around those tables [help]... there are common issues and... often times people just need an opportunity to kind of debrief.

Other than these meetings, there was not a lot of mention of mandatory formal structures put in place to help front-line workers cope with daily stressors and prevent burnout. Several of the key informants did mention that workers at the facilities had access to employee assistance programs that were free of charge. However, employees had to initiate accessing these programs when they were in need of help.

Coping with grief. Death is a significant event not only for the family, but also for the long-term care staff who have cared for the residents before and during death (Brazil et al., 2004). When asked what was the most challenging thing about caring for the dying, one key informant responded that it, "...would be the emotional needs, because that takes a chunk out of the [care provider] as well." It has been discussed that one of the

enhancers to quality hospice palliative care in the long-term care setting is the relationships that staff are able to form with residents. These relationships can also be a barrier to the care providers ability to carry out his or her role. It is possible that because of these caring relationships, care providers in the long-term care setting are more at risk for experiencing grief and loss than care providers in other care settings. It follows that grief support should be in place on an ongoing basis for workers in the long-term care setting.

Sebag-Lanoe et al., (2003) reported on a hospice palliative care program in France in which there has been a very proactive approach to supporting care workers in their grief. In this program, psychoanalysts meet with staff at regular intervals to talk of the difficulties attached to caring for the dying. It was felt that this approach to staff support had been very effective. When asked about grief support, key informants often discussed the same debriefings and team meetings that were used to support them in their daily roles. Preventative measures, however, did not seem to be in place.

In addition to team meetings and debriefings, key informants talked about participating in a variety of different memorial services. For example, it was explained that some care providers made an effort to go to the funerals of residents who had died. Key informants felt that this helped front-line workers to deal with their grief and at the same time show additional support to the family.

Most of the facilities also held memorial services at regular time intervals. For example, one facility had a memorial service every three months that paid tribute to all residents who had died in the previous three months. According to key informants, unit staff were encouraged to attend these services as a means of facilitating the grieving

process. Another facility had a very unique service for each individual resident who died,

One of the things that we do is we have candle light services... It's not a memorial service. But, it's more of a celebration of the resident's life... we... get together in the house where the resident lived and we invite the family to come... And we sit down and we light a candle and we talk about the resident as we knew them... And we talk about the good times and we talk about the sad times and share lots of stories... It was done, actually, in response to a request from the staff... for something to recognize that there's a loss for them as well as for the families.

Key informants from the above facility are the only ones who mentioned an ongoing program that specifically recognized and aimed to support the grief of staff members at the facility. These rituals of mourning are necessary to help care workers carry on with their roles caring for the dying (Sebag-Lanoë et al., 2003). This is an area than can be identified as a service gap at other facilities where key informants discussed team meetings and debriefings that occurred more on an "as needed" basis.

Implications of staff support. Education and training for staff at all levels is an enhancer to quality hospice palliative care. Whether education occurs through attendance at a national research conference or a unit in-service skills session, quality care is facilitated through expanded empirical knowledge. This knowledge allows staff to deliver the most up-to-date and competent care with confidence. Key informants expressed this to be a great support in their daily roles. It is recommended that both unit staff and management level staff be encouraged and supported by the facility to participate in ongoing education as a means of ensuring quality hospice palliative care service delivery. Education and training should be facilitated through in-house training sessions and financial support to attend educational events external to the facility, such as research conferences.

When asked, key informants reported that they felt supported in their daily roles.

There are a wide variety of informal and formal supports available within the studied facilities. Each of these supports is considered to be an enhancer to quality hospice palliative care service delivery as they allow care workers to carry out their daily care tasks while avoiding burnout. It is recommended that all the methods used by these facilities to support staff be considered as viable options for supporting staff by policy makers and management at other long-term care facilities.

Even though none of the reported methods of staff support are considered to be barriers to quality care, there are still some potential areas of improvement. In particular, the more formal methods of support, such as team debriefings and employee assistance programs, are reactive rather than proactive. These methods are used in response to emotional need or crisis instead of preventing the crisis to begin with. It is recommended that policy makers and facility management consider some proactive solutions to supporting staff that may help to prevent crisis instead of reacting to. Examples may include care provider support groups within the facility or regular visits to staff by qualified counselors or therapists (Sebang-Lanoë et al., 2003).

The Canadian Hospice Palliative Care Association's *A Model to Guide Hospice Palliative Care* (Ferris et al., 2002) was used as an overarching framework to guide data analysis in this research study, because it was the best available model. However, the model was developed primarily using empirical knowledge derived from research studies completed in the home care and acute care settings. To date there has been very little research completed on hospice palliative care service delivery in the long-term care setting. Long-term care may be considered to be a very unique care setting. Although long-term care is institutionalized care, it is also considered to be the resident's home.

Lengthy resident stays at the facilities result in relationship being formed between staff and residents. For this reason, staff support is an area of the CHPCA model that may be very different in the long-term care setting as compared to acute care or home care settings.

The CHPCA model states that staff should receive, “ongoing support to ensure the staff’s physical, psychological, and spiritual well-being” (Ferris et al., 2002, p. 48). The model also states that this support is integral to the provision of hospice palliative care. This support can be considered especially important when one takes into account the findings of this study that indicate that relationships formed between staff and residents are an enhancer to quality hospice palliative care service delivery. At the same time, these relationships contribute to the grief experienced by staff when a resident dies.

Although the model includes staff support as an integral component of hospice palliative care, staff support is included in the Square of Organization as opposed to the Square of Care. The model states that the squares are intended to be used with one another. However, several key informants stated that they see the residents as part of a family and that they feel significant grief when residents die. It follows that staff require care and support that is more on the level of that received by the family. In addition, acknowledgement of the integral contribution of staff needs to be reflected in the CHPCA model. At present, staff support is notably absent from the domains of care in the CHPCA model.

Front-line workers interviewed often referred to residents as being like members of their family or as surrogate family members. For this reason, it recommended that policy makers in long-term care consider staff support to be part of the Square of Care,

instead of the Square of Organization. It is further recommended that staff support be added as a domain of care. This may serve to place greater importance upon the emotional needs of care providers in this unique care setting.

Resources

In a focus group study, it was determined that management level nurses believed that residents received the highest quality care when they were allowed to remain in the long-term care facility where the staff knew them instead of being transferred to acute care. The exception to this was when the facility did not have the technological resources to meet the needs of the resident. The same study found that inadequate technological and personnel resources influenced staff decision to transfer residents to acute care (Bottrell et al., 2001). In keeping with this finding, the CHPCA model recognizes that a hospice palliative care programs must be adequately resourced to be effective (Ferris et al., 2002).

All of the key informants believed that the funding provided to them by VAC was an enhancer to quality hospice palliative care. This was especially true when key informants were asked to compare their own programs to those of other local long-term care facilities. They expressed concern that other publicly funded or not-for-profit facilities did not have adequate funding dedicated to hospice palliative care service delivery and that this may have a direct negative effective on quality of life at the end-of-life at those facilities. Adequate dedicated funding was found to enhance quality of care received through a wide range of services, the provision of specialized equipment, adequate human resources.

Range of services. All key informants were asked how their hospice palliative care programs differed from those at other facilities in their region. Several stated that

they were able to offer a much wider array of services than other facilities. It was suggested that they had access to all services that were necessary to provide quality care at the end-of-life. When asked, none of the key informants indicated that there were services missing that they would like to have added to the programs. Key informants were also asked about services that were available 24-hours a day. All responded that although not all services were available around the clock, the necessary services were available at least on-call, and that no services needed to be added. Several key informants also discussed complimentary therapies that were being introduced at the facilities that they felt improved quality of life such as aromatherapy, pet therapy and massage therapy. One nurse manager added that some of these therapies were made possible through VAC funding and provided massage therapy as an example.

Specialized equipment and space. Onsite supplies and diagnostic equipment are essential to the provision of quality hospice palliative care (Brazil et al., 2004). Key informants were asked if they had access to all the equipment necessary to ensure the highest possible quality of life at the end-of-life for the residents in their care. Again, several of the key informants indicated that due to the funding received from VAC they had access to anything they needed. Specialized equipment included lifts, whirlpool baths, and special beds. It was also discussed that if the necessary equipment needed was not owned by the facility it could often be rented from medical supply companies.

Key informants also discussed the physical space available to them as it was relevant to quality of life. For example, at one facility community needs assessments were done when funding was received for a new building. Key informants from that facility believed that the design of the resulting facility provided better social well-being

and ease of movement than did traditional structures. A nurse from another facility talked about a “green room” with plants and birds that was a place where many residents would go to relax or even meditate. During participant observations, I was able to see the courtyard garden that was maintained by the recreational therapy staff at the facility and the residents themselves. This garden was intended for the use of residents and families only, not for the staff, making it was a place where residents could go that did not feel like an institution.

Even with the higher level of funding available, one key informant pointed out that further funding was still necessary to make needed improvements within her facility. Specifically, she felt that the inside of her facility had an “institutional feel” and that the décor was very dated. She felt that improvements to the interior of the facility to make it feel more like a home could have a positive effect on the emotional well-being of the residents.

Human resources. One of the human resource management practices that appears to set VAC facilities apart from many other long-term care facilities is the level of knowledgeable staffing available. While other facilities face ongoing issues with adequate staff (Brazil et al., 2004), make use of registered nurses only in management level roles and use personal care workers for the bulk of front-line workers, four out of five of the facilities in this study used licensed practical nurses and registered nurses for their unit teams. One of the palliative care coordinators in the study stated that this level of skill at the bedside was important as a means of providing quality care.

In addition to front-line workers, several key informants believed that they had greater access to specialists such as physiotherapists, occupational therapists, and social

workers than did other facilities and that this had a direct impact on the quality of care received. It was suggested that the specialists were not spread as thin as they might otherwise be. For example, the nurse manger from one facility pointed out that the province provided funding for only one social worker at the facility, but that VAC provided the funding necessary for a second social worker.

However, with the high level of skill on the front-line, several key informants felt they were spread thin at peak times. For example, during participant observations it was noted that the number of staff was decreased on the unit during the evening and on the weekend. According to observed staff, weekend did not seem to be an issue, but from 5:00 pm to 10:00 pm 50% of the daytime staff compliment was available to ensure that each resident received their medications, was feed, and was prepared for bed. During observations it was noted that often front-line workers would not get a break during the evening shift. At 11:00 pm the number of staff on the unit was decreased by one more, but it was suggested that unless there was a crisis on the unit the number of staff was sufficient for the night shift.

Several key informants did indicate that there was a need to be able to call in additional staff members during health crises or expected deaths. At some facilities, provisions were made for additional staff during these times, but often this had to be arranged during the day. If the crisis happened at night, unit staff had to wait until morning to call in additional care workers. At other facilities, unit staff had to work together to ensure the floor was covered. Often one nurse would be assigned to the dying resident and his or her family and the rest of the staff would take on a heavier load. Usually, volunteers could be called into sit with the resident through the day and night if

family was not available or needed respite. Again, the limitation to this was that it had to be arranged during the day. If a crisis happened during the night, unit staff were unable to call in volunteers.

Implications of resources. Dedicated funding from VAC was seen as an enhancer to quality care by all of the key informants interviewed. Key informants noted that the level of funding offered by VAC allowed for a wide variety of services, specialized equipment, relaxing spaces, and skilled workers that were often not available at other not-for-profit facilities. Based on the data collected, adequate funding allowing for all the above resources greatly enhanced the holistic care received at the participating facilities. Ideally, this level of funding would be available at all long-term care facilities in Canada.

However, even with a relatively high level of funding barriers to care still existed. One key informant mentioned the “institutional feel” of the facility where she worked. Another key informant referred to wards in which several residents were required to co-exist in the same room. This situation left residents greatly lacking in privacy. In addition, while human resources were considered to be far greater than conditions that existed in other long-term care facilities, key informants suggested that at crisis times, such as when a resident was actively dying, they would benefit greatly from an additional staff member being added to the unit. This would allow one nurse to focus solely on the dying resident and his or her family. It is recommended that when facilities review their budgets or receive additional funding that resident accommodations, additional staffing and overall hospice palliative care program development be considered as worthy receivers of budgeted expenses.

Limitations

The findings of this study are limited by several aspects of the research design. As previously mentioned in the description of the overarching theoretical framework, the CHPCA model was developed primarily utilizing empirical knowledge gained in the home care and acute care sectors. Essentially, the model used was the best available fit. However, had a model been available that was focused on the unique aspects of hospice palliative care in the long-term care setting, the interview guide developed may have differed and gleaned alternative data.

A second limitation is the population and sample selected for this study. The population was restricted to facilities contracted by Veterans Affairs Canada. This meant that the vast majority of residents at the participating facilities were Caucasian males of Judeo-Christian faiths who were either English or French speaking. Hospice palliative care guidelines require that facility staff be sensitive to diverse cultural, ethnic, and spiritual needs. It was difficult to ascertain how this is done in the long-term care environment with such a homogenous resident population.

In addition to the homogeneity of the resident population, the scope of the study was further restricted by the characteristics of the participating facilities. All participating facilities were fairly large with the smallest having 175 beds. According to key informants, all facilities were very well funded by Veterans Affairs Canada relative to other publicly funded facilities. Several of the facilities had collaborative relationships with acute care facilities in the region that further added to their resourcing. In contrast, many long-term care facilities are much smaller in size and have far fewer resources than the participating facilities. Future research should be directed at the applicability of these

study findings in the long-term care environments that are more diverse in culture and more varied in size and level of funding.

Finally, the perspective of the participants is also a limitation to this study. The research design focused on the perspective of front-line care workers and management level nurses as it pertained quality service delivery of hospice palliative care. This perspective is significantly important fully understanding the definition of high quality hospice palliative care service delivery in the long-term care setting. However, this cannot be completely and truthfully defined without the voices of all key stakeholders. In particular, this study is lacking the perception that could be provided by the receivers of care, namely the residents and their loved ones, and specialist care providers such as physicians, social workers, pastoral care workers, and psychologists. Future research should focus both on the perspective of these parties and their particular roles in care.

Conclusions

This study aimed to contribute to the body of existing empirical knowledge pertaining to hospice palliative care service delivery in the long-term care setting. This goal was attained through a multi-methods approach to defining and assessing high quality care in long-term care facilities contracted by Veterans Affairs Canada to provide care to Canada's aging war Veterans. The two research questions asked attempted to determine what components constituted a high quality hospice palliative care program in the long-term care setting and what barriers and enhancers existed to facilitating such a program.

It was determined that for the most part, the component required to deliver a high quality hospice palliative care program in the long-term care setting matched the domains of care included in the CHPCA model. There were two exceptions to this finding. The first exception is that the Practical Care Domain did not seem to apply in LTC. Practical care included things like telephone use and transportation. These were components of care that would not differ significantly for residents who received hospice palliative care services.

The second exception was that staff support was missing as a domain of care. Lengthy resident stays in long-term care make this care setting unique. Although LTC is institutionalized care, most residents live there long enough that it also becomes their home. Due to the nature of the facility, staff and residents form trusting and caring relationships that are assumed not to be formed as often in other care settings. Therefore, care workers seem to feel a deeper sense of grief at the loss of a resident and should be considered as part of the unit of care. It is recommended that staff support be developed

as a required component of a quality hospice palliative care program and be seen in a similar light as family support. This support should include both emotional support and ongoing training and education to help facilitate daily care roles.

The norms of practice also included items that varied in the long-term care setting. Most notably the role of family caregivers seemed to differ. The norms of practice included requirements that family caregivers be educated on issues like proper procedures for giving medications. When asked about the role of family members and other caregivers, key informants indicated that due to liability issues these individuals would never be given the responsibility of ensuring medications were properly received. They also indicated that family members were not involved in the bulk of physical care and most did not want to be so involved. Physical care performed by family members was limited to grooming and feeding. The role that the family played on the care team applied more to the social and emotional well-being of the resident than it did to physical care. Further research should be directed at understanding the family role in care and guiding policy makers in considering this role in long-term care.

There were two areas of the norms of practice that did not seem to apply to hospice palliative care specifically. Instead they applied to overall care more generally. These were infection control and safety practices. In long-term care these care area had policies of their own instead of being components of hospice palliative care policy. However, this study is limited in scope by the size of the facilities in the sample populations. All facilities were large institutions. Further research is necessary to understand how infection control and safety guidelines are applied to hospice palliative care policy in smaller long-term care facilities.

The CHPCA model was selected as an overarching framework for this study, because it was the best available model. Overall, the model seemed to apply well in the long-term care setting, with a few notable exceptions. Further empirical knowledge is necessary to develop a model that is specific to long-term care and would then guide policy makers and decision makers in this unique care setting.

It is assumed that in the long-term care setting, a lack of resources is a barrier to quality hospice palliative care. The funding provided by VAC to the facilities participating in this study allowed the research design to uncover the barriers and enhancers that existed to facilitating a quality hospice palliative care program in the long-term care setting when resources were less of a factor. Facility collaboration with external hospice palliative care organizations further ensured that the maximum levels of resources were available to facility residents. This collaboration was seen as an enhancer to care. It should be noted that many key informants acknowledged the participating facilities received higher levels of funding than did other publicly funded facilities in their localities. However, even with the level of funding available and the aforementioned collaborations, key informants reported that human resources were strained during crises periods and believed that additional staffing would enhance care received during an expected death. When one considers this finding in combination with demographic projections for our aging population, a light is shone upon the necessity for improved levels of funding for hospice palliative care programs in all publicly funded long-term care facilities in Canada. Ideally, all facilities would be funded at or above the levels of funding provided to participating facilities.

Other enhancers to high quality hospice palliative care service delivery included

knowledge-based policies, skill and education levels of front-line staff, availability of specialist care, a team approach to care, open and honest communication, modified care planning, continuity of care, ongoing nursing and specialist assessments, sensitivity to need, program evaluations, family physical and emotional support during the death event, staff support through continuing education opportunities, informal staff supports, and physical resources. One of the most significant findings of this study was the understanding of the relationships that formed between staff and residents in long-term care and how these relationships could enhance care. Key informants felt that these relationships were part of what made long-term care unique as compared to other care settings. Lengthy resident stays coupled with consistency in staffing allowed staff members time to gain an in-depth understanding of each individual resident's needs and wishes. Front-line staff felt they were valued members of the care team as physicians and other specialists valued their opinions and knowledge regarding the residents in their care.

Although relationships between residents and staff were a significant enhancer to quality care, they could also be a barrier to care. Key informants reported that they felt substantial grief after the death of a resident. This presented a challenge to the daily caring roles of front-line workers in particular. Although this grief was felt and reported, it did not seem to be fully recognized by the hospice palliative care policies in practice at all of the participating facilities. Care providers were encouraged to attend memorial services and funerals, unit managers organized de-briefings following difficult deaths, and co-workers looked to one another for emotional support, but all of these practices were reactive in nature. There were no instruments in place to support staff emotionally

in a proactive way.

Within the CHPCA model, staff support is listed sparingly in the chapter guiding organizational develop and is not mentioned at all in the chapter pertaining to resident and family care. It is recommend that policy makers consider staff support as an important component of hospice palliative care policy and that decision makers put into place emotional supports that contribute to the emotional health of care workers on a more regular and proactive basis. Implementing more proactive approaches to staff support may also lead to better retention of care providers in this care setting and further facilitate the trusting relationships that form between residents and staff.

There were several challenges that were determined to be barriers to quality hospice palliative care in addition to the grief felt by care workers. These included psychological and spiritual care for residents, staff comfort levels with discussing death and dying, interpersonal conflict, cultural diversity in an homogenous population, family support in preparedness for transition to comfort care, and a lack of dedicated bereavement care programs.

Although this study is limited in scope by the sample population utilized, it presents a wide range of issues that require further consideration and study. Future research is needed to understand how hospice palliative care is understood from the perspective of other key stakeholders, such as residents, family members, and specialist care providers. It is hoped that the knowledge gained in this study will be used to inform and guide policy makers and decision makers in the development, implementation and evaluation of current and future hospice palliative care policies and programs in the long-term care setting.

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Appendix A- Letter to Key Contacts

I. Project Description

Introduction

Hospice palliative care is an approach to the care of chronically and terminally ill individuals that has received increased attention in recent years. Nurses and staff in long-term care facilities have long had to address the end-of-life care needs of terminally ill residents. However, there is very little evidence-based knowledge available to guide care decisions in this area. No national framework has been developed to guide palliative care service delivery in the long-term care setting. The current study aims to increase the body of knowledge surrounding how this type of treatment is best delivered.

Research Objectives

The main objective of the current study is the development of best practice guidelines for palliative care service delivery in the long-term care setting. This objective will be achieved by answering the following two research questions:

1. What are the components of a best practice palliative program in the long-term care setting?
2. What are the barriers and enhancers to developing a best practice palliative care program in the long-term care setting?

The population being studied are long-term care facilities in Canada that are contracted by Veterans Affairs Canada (VAC) to provide services to Veterans who qualify for long-term care benefits.

The Researcher

This research is being conducted by Shannon McEvenue, a graduate student at Mount Saint Vincent University, in partial fulfillment of the requirements for completion of a Master of Arts in Family Studies and Gerontology. The research will be guided by the thesis advisor, Dr. Janice Keefe, Associate Professor at Mount Saint Vincent University and Canada Research Chair in Aging and Caregiver Policy. The project has received financial support in the form of a Student Research Award from the Nova Scotia Health Research Foundation. Ethics certification has been granted by the MSVU University Research Ethics Board.

Implications and Outcomes

The findings of this study will add to the currently expanding body of literature relevant to hospice palliative care policy-making and service delivery in the long-term

care setting. Findings will be of interest to long-term care policy-makers within Veterans Affairs Canada, the long-term care community, and provincial- and federal-level government. Service providers will also be able to make immediate use of study findings in terms of policy and program development.

For additional information please contact:

Shannon McEvenue
Mount Saint Vincent University
Halifax, NS
Phone: (902) 420-1765
Email: shannonmcevenue@hotmail.com

Dr. Janice Keefe, Ph.D.
Mount Saint Vincent University
Halifax, NS
Phone: (902) 457-6466
Fax: (902) 457-6134
Email: janice.keefe@msvu.ca

II. Letter to Key Contact

Date

Dear Key Contact,

My name is Shannon McEvenue. I am a graduate student in the Master of Arts in Family Studies and Gerontology program at Mount Saint Vincent University in Halifax, Nova Scotia. I am currently undertaking thesis research, entitled *Palliative Care in Long Term Care: Best Practices in Service Delivery*, towards the completion of my degree. Your facility has been identified by *Veteran's Affairs Canada* for its provision of high quality care in the areas of palliative and end-of-life care.

I am writing to you today to request your help in attaining the main objectives of this research project. These objectives include (a) identifying the components of a “best-practice” palliative care program in the long-term care setting, (b) identifying barriers and enhancers to developing a ‘best-practice’ palliative care program in the long-term care setting, and (c) developing best-practice guidelines for palliative care programming in the long-term care setting. This data collection will involve analysis of written policies, interviews with front-line workers, and in-field shadowing of front-line workers.

For your part, I am requesting two actions. The first is that you make available any written policies pertaining in whole or in part to palliative and/or end-of-life care at your facility. This may be done by either email attachment or through regular mail. The second is the provision of names and contact information of nurse managers, nurses, and personal care workers at your facility who may be willing to participate in a 1-2 hour interview pertaining to palliative care service delivery. These workers should have daily experience in this field. Although only one front-line worker and one nurse manager will be interviewed, please forward the names of all individuals you feel would be able to provide valuable information in this process. The selection of two participants will be made for this list.

All graduate research must receive approval in accordance with the ethical guidelines set out by the Mount Saint Vincent University Research Ethics Board (Please see ethics certificate attached). I would like to stress that the participation of your facility in this study is entirely voluntary. Any workers who you may identify for participation will also have the option of declining to be interviewed or shadowed. I would also like to emphasize that should you decide to participate, the participation and that of any of your employees will be confidential and anonymous. No reference to facility or individual names will be made in any report resulting from this study.

I would like to thank you in advance for your consideration in this matter. The final report of this study will be made available to you at your request. If you have any questions or concerns please contact either myself or Dr. Janice Keefe.

Shannon McEvenue
Graduate Student
Mount Saint Vincent University
(902) 420-1765
shannonmcevenue@hotmail.com

Dr. Janice Keefe
Thesis Advisor
Associate Professor
Mount Saint Vincent University
(902) 457-6466
Janice.keefe@msvu.ca

If you would like to speak to someone outside of the research project, you may contact:

Chair, University Ethics Review Committee
c/o MSVU Research Office
166 Bedford Hwy, EV 136
Halifax, Nova Scotia
B3M 2J6
(902) 456-6350
research@msvu.ca

Sincerely,

Shannon McEvenue

Appendix B- Interview Questions

I. Interview Guide

Good morning/afternoon/evening. I would like to thank you for agreeing to be interviewed for this study focusing on palliative care policies in long-term care facilities. The framework for the study is the Canadian Hospice Palliative Care Association's model for service delivery. As a result, the structure of the interview is guided by the layout of the model. However, for the most part the questions are quite broad, allowing us to explore the uniqueness of the programs at your facility.

1. Could you begin by describing the palliative care program at your facility?
 - When is it delivered
 - Why is it delivered
 - Definition/goals/objectives
 - Guiding model
 - Services offered
 - Palliative care team
2. How do residents and families access the palliative care program at your facility?
 - Assessment
 - Requirements
 - Consultation
 - Education of residents and families
 - Privacy
3. Could you describe the process used to develop and maintain a care plan for a resident receiving palliative care?
 - Physician consultations
 - Respect for confidentiality
 - Need for further information
 - Diagnosis/prognosis
 - Desire not to know
 - Team meetings
 - Social worker involvement
 - Language barriers
 - Decision-making capacity
 - Decision-making assistance
 - Primary responsibility
 - Use of proxy decision-maker
4. In what ways does your facility attempt to take into account the many variables affecting each resident's needs individually? i.e. culture, language, autonomy

- Skills set available
 - Resources available
 - Time available to spend with each individual
5. Who carries out the implementation of the care plan?
 - Nursing staff
 - Family involvement
 - Maintenance of continuity of care
 6. What services are available around the clock at your facility? What services are not available around the clock, but should be to provide the best care possible?
 7. What steps have been taken to ensure that your program is delivered in a safe and effective manner?
 - Infection control
 - Safe and up to date equipment
 - Protocol for documenting errors
 8. What types of information are collected regularly at your facility?
 - Care plan
 - Resident charts
 - Statistics
 9. Do you collaborate with anyone outside of your immediate organization to ensure that resident needs are being met? To stay up to date on current standards of practice and new knowledge in the field?
 10. Are there enablers or enhancers that facilitate the delivery of a high quality palliative care program at your facility?
 - Funding
 - Champion
 - Management on board
 - Government support
 - Research
 - Advocacy
 11. Which resident needs are being readily met?
 12. What are the challenges exist to providing the highest quality palliative care program?
 - Gaps in service
 - Unmet needs
 - Resources issues

- Time available to spend with resident address various needs including answering questions, addressing concerns, and ensuring that all information is shared
- Biggest challenge?

13. Are there solutions?

14. As a member of the staff at your facility, do you feel that you are adequately supported in your role?

15. What are some of the unique challenges and opportunities to providing palliative care in the long-term care setting that may not be as prevalent in other settings?

16. Finally, could you share a success story that you feel describes the high quality of your palliative care program?

17. Are there any areas that you feel are particularly pertinent that have not yet been discussed?

II. Questions Sent to Interview Participants

<p>Palliative care in long-term care: Towards best practices in service delivery Researcher: Shannon McEvenue BSc, MA (Candidate)</p>

Interview Questions: Data Collection Stage Two

1. Could you begin by describing the palliative care program at your facility?
2. How do residents and families access the palliative care program at your facility?
3. Could you describe the process used to develop and maintain a care plan for a resident receiving palliative care?
4. In what ways does your facility attempt to take into account the many variables affecting each resident's needs individually? i.e. culture, language, autonomy
5. Who carries out the implementation of the care plan?
6. What services are available around the clock at your facility? What services are not available around the clock, but should be to provide the best care possible?
7. What steps have been taken to ensure that your program is delivered in a safe and effective manner?
8. What types of information are collected regularly at your facility?
9. Do you collaborate with anyone outside of your immediate organization to ensure that resident needs are being met? To stay up to date on current standards of practice and new knowledge in the field?
10. Are there enablers or enhancers that facilitate the delivery of a high quality palliative care program at your facility?
11. Which resident needs are being readily met?
12. What are the challenges exist to providing the highest quality palliative care program?
13. Are there solutions?
14. As a member of the staff at your facility, do you feel that you are adequately supported in your role?

15. What are some of the unique challenges and opportunities to providing palliative care in the long-term care setting that may not be as prevalent in other settings?
16. Finally, could you share a success story that you feel describes the high quality of your palliative care program?
17. Are there any areas that you feel are particularly pertinent that have not yet been discussed?

Appendix C- Informed Consent

I. Informed Consent for Interviews

Consent to be Interviewed

I, _____, consent to participation in the research study entitled *Palliative Care in Long-Term Care: Best Practices in Service Delivery*. I have read a description of the study and understand its goals and objectives. I have had an opportunity to ask questions of the researcher to ensure that I understand what is expected of me. This study has received ethics approval in accordance with guidelines set out by the Mount Saint Vincent University Ethics Committee.

I understand that the researcher will interview me regarding my daily activities as they pertain to services provided to our residents receiving hospice palliative care. The interview will take place either in person or by telephone at a time that is convenient to me and will last approximately 1-2 hours. I understand that this interview will be taped and transcribed.

The researcher has explained to me that my participation in this study is entirely voluntary. I have the right to decline participation, to refuse to answer questions I am not comfortable with, or to withdraw from the interview at any time. While the facility director has identified me as a potential candidate for participation, my decision to decline participation will have no impact on my job or employment. Nor will my decision not to participate impact negatively on the facility that I work at in any way.

I understand that all responses that I make during the course of the interview will be kept confidential. Tapes and documents will be kept secure at all times during the study and will be destroyed upon completion of the study. The only individuals who will have access to these items will be the researcher and her thesis advisor, Dr. Janice Keefe from Mount Saint Vincent University. Actual participant names will not be used at any time and pseudonyms will be used for transcriptions. While passages taken from interviews may be used, at no time will my name or the facility name be used in relation to these passages or in the dissemination of study findings.

A final report of the study findings will be made available to me upon my request.

Signed,

Date

Further information or final reports may be obtained by contacting either Shannon McEvenue or Dr. Janice Keefe.

Shannon McEvenue
Graduate Student
Mount Saint Vincent University
(902) 420-1765
shannonmcevenue@hotmail.com

Dr. Janice Keefe
Thesis Advisor
Associate Professor
Mount Saint Vincent University
(902) 457-6466
janice.keefe@msvu.ca

If you would like to speak to someone outside of the research project, you may contact the Mount Saint Vincent University Research Office:

Chair, University Ethics Review Committee
c/o MSVU Research Office
166 Bedford Hwy, EV 136
Halifax, Nova Scotia
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(902) 456-6350
research@msvu.ca

*II. Staff Informed Consent- Participant Observations***Consent to Participate in a Research Study
Participant Information**

Study Title: Palliative Care in Long-Term Care: Best Practice in Service Delivery

Principle Investigator: Shannon McEvenue
Graduate Student
Mount Saint Vincent University
166 Bedford Hwy
Halifax, NS, B3M 2J6
Telephone: (902) 420-1765
Email: shannon.mcevenue@msvu.ca

Thesis Advisor: Dr. Janice Keefe
Associate Professor
Canada Research Chair in Aging and Caregiver Policy

Study Sponsor: Nova Scotia Health Research Foundation
Part A

Clinical Trials and Research Studies**1. Introduction**

You are invited to join a research study. The study is being offered by a graduate student in the Department of Family Studies at Mount Saint Vincent University. This study is being undertaken to understand how services are delivered in facilities such as yours. This information will help you decide if you want to be a part of the study or not. Your participation is voluntary. Your decision not to participate will not affect your performance evaluation in any way.

2. What Will I Learn From Reading This?

We will explain why we are conducting this research study. We will also tell you what will happen, and about any inconvenience, discomfort, or risks.

Please read this carefully. Take as much time as you like. If you like, take it home to think about for a while. Mark anything you don't understand, or want explained better. After you have read it, please ask questions about anything that is not clear. You may also contact the researcher by telephone. Contact information is included at the end of this form.

3. What is a Research Study?

A research study is “an organized investigation of some question(s) that can be answered by the collection and analysis of appropriate information”. They are a way of finding out new information that may help other people in similar circumstances as yours.

In this study we will want to understand how palliative care services are delivered at your facility. This information will contribute to the development of best practice guidelines for hospice palliative care service delivery in the long-term care setting.

4. Do I Have to Take Part In This Study?

No! It is completely up to you. Whether you take part or not is for you to decide. You may want to show this to your family, friends or your family doctor before you make up your mind. Please feel free to get other opinions any time.

No matter what you decide, we will support your decision. Your decision not to participate will not affect your performance evaluation in any way. No one will be upset with you if you decide not to take part or change your mind.

If you do decide to take part, you can still change your mind and stop participating at any time.

5. Will The Study Help Me?

We do not know. The purpose of this study is to identify the best possible methods for delivering hospice palliative care services in the long-term care setting. We would also like to understand what helps or hinders workers to deliver the best possible care. The incorporation of the findings of this study into your day-to-day care delivery should help you to better meet the needs of residents receiving hospice palliative care services at your facility.

Part B

Explaining the Study

6. Why Am I Being Asked to Join This Study?

Your facility has been identified by Veterans Affairs Canada for high quality palliative care service delivery. The aim of these field observations is to understand how hospice palliative care services are delivered at your facility. You have been asked to participate in this study, because you are a frontline worker on staff in this unit.

7. Why Is This Study Being Done?

The main objective of the current study is the development of best practice guidelines for palliative care service delivery in the long-term care setting. This objective will be achieved by answering the following two research questions:

1. What are the components of a best practice palliative program in the long-term care setting?
2. What are the barriers and enhancers to developing a best practice palliative care program in the long-term care setting?

8. How Is This Study Being Done?

This is the third of three steps of data collection being undertaken in this study. In the first step, written hospice palliative care policies were collected from several long-term care facilities across Canada to understand the frameworks that these facilities use for delivering palliative care services. In the second step of data collection interviews were conducted with a nurse manager and a front-line worker at each of the participating facilities to create an understanding of how these policies are implemented. In the third and final step we will be observing front-line workers as they deliver all types of services, including palliative care, on a day-to-day basis. This step will be carried out on your unit only.

While observations are taking place you will not be expected to change your daily routine in any way. The researcher will follow you as you go through your daily routine. Notes will be taken under various headings such as resident diagnosis, assessment, information-sharing, decision-making, care planning, care delivery, and confirmation. During breaks the researcher may ask you questions about the tasks you have carried out during the day. Notes may be taken at this time as well.

The researcher will be visiting your unit in the week prior to the study to talk to residents about study participation. The researcher will only be observing you as you deliver care to those residents who have consented to participation.

It should be noted that any field notes taken will be kept entirely confidential. The only people who will have access to these notes will be the researcher and the thesis advisor. At no time will your supervisor or anyone else at your facility have access to these documents. In addition, these documents will be kept on the researcher's person or in a locked file at all times.

9. How Long Will I Be In This Study?

Observations are planned to take place over a seven-day period. You are being asked to consent to participation for two to three shifts during this period of time.

10. Can I Be Taken Out of The Study Without My Consent?

While this study is planned to take place over a seven-day period of time, observations may be halted before this period has entirely passed. This would only happen if it is determined that no new information can be obtained by continuing.

11. How Many People Will Take Part In This Study?

Five facilities nation-wide participated in the first two stages of data collection. This included one facility from each of the five regions of Canada; Atlantic, Quebec, Ontario, Prairies, and British Columbia.

In this stage of data collection, only members of your nursing unit are being asked to participate. We are looking to recruit 3-4 front-line workers for participation in this study. We would like to observe as many unit residents as possible, though the residents must have consented to participate in this study for the researcher to observe you providing care to them.

12. Who Can Take Part In This Study?

You may volunteer to participate in this study if:

- ✓ You are 18 years of age or older
- ✓ You are a personal care worker, licensed practical nurse, or registered nurse providing direct resident care

13. What Will Happen If I Take Part In This Study?

You are asked to continue in your regular daily routine as you usually would while you are being observed. At the conclusion of each shift you will have the opportunity to ask questions of the researcher and to explain anything that you feel is relevant. At the conclusion of the study you will receive a copy of the final results of the study.

14. Are There Risks To The Study?

During field observations the researcher will be openly shadowing you as you go through your daily tasks. Because it is impossible to prevent other staff members and unit residents from seeing, it is impossible to guarantee that your participation will be anonymous. However, as previously mentioned, any observations will be confidential. No one, other than the researcher, her supervisor, the Capital Health Ethics Board and their auditor will have access to the field notes.

The exception to the guarantee of confidentiality is the witnessing of abuse. This would include both abuse of a nurse by a resident and abuse of a resident by a nurse. Should the researcher bear witness to any abuse as defined by the Department of Justice Canada she would be morally and legally bound to report this abuse to the proper authorities.

15. What Are My Responsibilities?

In this study you will be requested to:

- ✓ Complete your daily tasks as you normally would
- ✓ Answer the researcher's questions about the care you are providing

16. Will This Cost Me Anything?

There will be no cost to study participants. You will not be paid to participate in this study.

17. What About My Right To Privacy?

We will do everything possible to keep your personal information confidential. Your name will not be used at all in your study records. If the results of this study are presented in a meeting, or published, nobody will be able to tell that you were in the study.

Your records will be kept until seven years following the thesis defense (scheduled for June 2005) in a secure area such as a locked file cabinet and office. Only the researcher, her supervisor, the Capital Health Ethics Board and their auditor will have access to the field notes. Information collected will not be used in final analysis should you decide to withdraw from the study.

18. What If I Want to Quit The Study?

If you choose to participate and later decide to change your mind, you can say no and stop the research at any time. A decision to stop being in the study will not affect your performance evaluation.

19. Declaration of Financial Interest

This research is being undertaken towards the completion of a Master of Arts in Family Studies and Gerontology. Student research funding has been provided by the Nova Scotia Health Research Foundation.

20. What About Questions Or Problems?

If you have any questions about this study please call Ms. Shannon McEvenue or Dr. Janice Keefe. Shannon McEvenue is in charge of this study at this hospital. Dr. Janice Keefe is the advisor and an Associate Professor in the Department of Family Studies and Gerontology at Mount Saint Vincent University.

Shannon McEvenue
c/o Maritime Data Centre
Room 360 Evaristus Building
Mount Saint Vincent University
166 Bedford Hwy
Halifax, B3M 2J6
Telephone (902)420-1765

Dr. Janice Keefe
Associate Professor
Canada Research Chair in Aging and Caregiver Policy
Maritime Data Centre
Room 360 Evaristus Building
Mount Saint Vincent University

166 Bedford Hwy
Halifax, B3M 2J6
Telephone (902)457-6466

If you would like to speak to someone outside of the research project, you may contact the Mount Saint Vincent University Research Office:

Chair, University Ethics Review Committee
c/o MSVU Research Office
166 Bedford Hwy, EV 136
Halifax, Nova Scotia
B3M 2J6
(902) 456-6350

20. What Are My Rights?

After you have signed this consent form you will be given a copy.

If you have any questions about your rights as a research subject, contact the **Patient Representative** at **(902) 473-2133**.

In the next part you will be asked if you agree (consent) to join this study. If the answer is “yes”, you will need to sign the form.

Part C 21. Consent Form and Signatures

I have read all the information about this study, which is called:

Palliative care in long-term care: Best practices in service delivery

I have been given the opportunity to discuss it. All my questions have been answered. I am satisfied with the answers.

I agree to allow the people described here to have access to my medical records.

This signature on this consent form means that I agree to take part in this study.

**Note: Please fill in the dates personally*

_____	_____	_____
Signature of Participant	Name (Please print)	Date

_____	_____	_____
Signature of Witness	Name (Please print)	Date

_____	_____	_____
Signature of Investigator	Name (Please print)	Date

_____	_____	_____
Signature of Person Conducting	Name (Please print)	Date

_____	_____	_____
Signature of Next of Kin (if req)	Name (Please print)	Date

I Will Be Given A Signed Copy Of This Consent Form

Thank you for your time and patience!

*III. Resident and Family Informed Consent- Participant Observations***Consent to Participate in a Research Study
Resident Information**

Study Title: Palliative Care in Long-Term Care: Best Practice in Service Delivery

Principle Investigator: Shannon McEvenue
Graduate Student
Mount Saint Vincent University
166 Bedford Hwy
Halifax, NS, B3M 2J6
Telephone: (902) 420-1765
Email: shannon.mcevenue@msvu.ca

Thesis Advisor: Dr. Janice Keefe
Associate Professor
Canada Research Chair in Aging and Caregiver Policy

Study Sponsor: Nova Scotia Health Research Foundation

Part A**Clinical Trials and Research Studies****1. Introduction**

You are invited to join a research study. The study is being offered a by graduate student in the Department of Family Studies at Mount Saint Vincent University. This study is being undertaken to understand how services are delivered in facilities such as yours. This information will help you decide if you want to be a part of the study or not. Your participation is voluntary.

2. What Will I Learn From Reading This?

We will explain why we are conducting this research study. We will also tell you what will happen, and about any inconvenience, discomfort, or risks.

Please read this carefully. Take as much time as you like. Mark anything you don't understand, or want explained better. After you have read it, please ask questions about anything that is not clear. You may also contact the researcher by telephone if you have any additional questions. Contact information is provided at the end of this form.

3. What is a Research Study?

A research study is “an organized investigation of some question(s) that can be answered by the collection and analysis of appropriate information”. They are a way of finding out new information that may help other people in similar circumstances as yours.

In this study we will want to understand how palliative care services are delivered at your facility. This information will contribute to the development of best practice guidelines for hospice palliative care service delivery in the long-term care setting.

4. Do I Have to Take Part In This Study?

No! It is completely up to you. Whether you take part or not is for you to decide. You may want to show this to your family, friends or your family doctor before you make up your mind. Please feel free to get other opinions any time.

No matter what you decide, we will support your decision. We will continue to give you the best possible care no matter what happens. No one will be upset with you if you decide not to take part or change your mind.

If you do decide to take part, you can still change your mind and stop participating at any time.

5. Will The Study Help Me?

We do not know. The purpose of this study is to identify the best possible methods for implementing hospice palliative care services in the long-term care setting. We would also like to understand the existing barriers and enhancers to delivering a best practice palliative care program in the long-term care setting. The incorporation of the findings of this study into the day-to-day delivery of care may help to improve the quality of life of those residents receiving hospice palliative care services at your facility.

Part B

Explaining the Study

6. Why Am I Being Asked to Join This Study?

The palliative care program at your facility has been identified by Veterans Affairs Canada a high quality. Your unit has been selected for field observations. All residents of your unit are being invited to participate.

7. Why Is This Study Being Done?

The main objective of the current study is the development of best practice guidelines for palliative care service delivery in the long-term care setting. This objective will be achieved by answering the following two research questions:

1. What are the components of a best practice palliative program in the long-term care setting?
2. What are the barriers and enhancers to developing a best practice palliative care program in the long-term care setting?

8. How Is This Study Being Done?

This is the third of three steps of data collection being undertaken in this study. In this third and final step we will be observing front-line workers as they deliver all types of services, including palliative care, on a day-to-day basis. This step will be carried out on your unit only.

This type of study is called a field observation. Observations are taken as people go about their daily basis. You will not be expected to change your daily routine in any way. The researcher will follow various staff members as they go through their daily routines. Notes will be taken using under various headings such as resident diagnosis, assessment, information-sharing, decision-making, care planning, care delivery, and confirmation. The researcher will observe staff members in the private rooms of those residents who have given consent only.

It should be noted that any field notes taken will be kept entirely confidential. The only people who will have access to these notes will be the researcher and the thesis advisor. In addition, these documents will be kept on the researcher's person or in a locked file at all times.

9. How Long Will I Be In This Study?

Participant observation is planned to take place over a seven-day period. You are being asked to consent to being observed as you receive care during this time frame.

10. Can I Be Taken Out of The Study Without My Consent?

While this study is planned to take place over a seven-day period of time, participant observations may be halted before this period has entirely passed. This would only happen if the researcher decides no new information can be obtained. The researcher may also decide to cease observations of individual residents if it is perceived that continued participation would cause undue distress to the resident.

11. How Many People Will Take Part In This Study?

Five facilities nation-wide participated in the first two stages of data collection. This included one facility from each of the five regions of Canada; Atlantic, Quebec, Ontario, Prairies, and British Columbia.

In this stage of data collection, only members of your nursing unit are being asked to participate. We are looking to recruit 3-4 front-line workers for participation in this study. We would like to observe as many unit residents as possible.

12. Who Can Take Part In This Study?

You may volunteer to participate in this study if:

- ✓ You are 18 years of age or older
- ✓ You are living on the unit being observed. You do not need to be receiving palliative care services to participate

13. What Will Happen If I Take Part In This Study?

You are asked to undertake your regular daily routine as you usually while you are being observed. The researcher will observe you and your nurse as you receive care. If you at

any time you would prefer to receive certain aspects of care in private, you may ask the researcher to leave. You may want to do this for only certain aspects of care or you may ask to withdraw from the study completely. It is up to you to decide. At the conclusion of the study the unit will receive a copy of the final results of the study. This may be made available to you upon your request.

14. Are There Risks To The Study?

During field observations the researcher will be openly shadowing you as you go through your daily tasks. Because other staff members and unit residents will be able to see this, it is impossible to guarantee that your participation will be anonymous. However, as previously mentioned, any observations will be confidential. No one, other than the researcher and the thesis advisor, will have access to the field notes. Eventually findings will be made public. However, at no time will your name or the name of your facility be used in the presentation of these findings.

The exception to the guarantee of confidentiality is the witnessing of abuse. This may include abuse of a resident by a nurse or the abuse of a nurse by a resident. Should the researcher bear witness to any abuse as defined by the Department of Justice Canada she would be morally and legally bound to report this abuse to the proper authorities.

15. What Are My Responsibilities?

In this study you will be requested to:

- ✓ Complete your daily tasks as you normally would

16. Will This Cost Me Anything?

There will be no cost to study participants. You will not be paid to participate in this study.

17. What About My Right To Privacy?

We will do everything possible to keep your personal information confidential. Your name will not be used at all in your study records. If the results of this study are presented in a meeting, or published, nobody will be able to tell that you were in the study.

Your records will be kept until seven months following the thesis defense (scheduled for June 2005) in a secure area such as a locked file cabinet and office. Only the researcher, her supervisor, the Capital Health Ethics Board and its auditor will have access to them,

and know your name. Information collected will not be used in final analysis should you decide to withdraw from the study.

18. What If I Want to Quit The Study?

If you choose to participate and later decide to change your mind, you can say no and stop the research at any time. A decision to stop being in the study will not affect your performance evaluation.

19. Declaration of Financial Interest

This research is being undertaken towards the completion of a Master of Arts in Family Studies and Gerontology. Student research funding has been provided by the Nova Scotia Health Research Foundation.

20. What About Questions Or Problems?

For more information about this study please call Ms. Shannon McEvenue or Dr. Janice Keefe. Shannon McEvenue is in charge of this study at this hospital. Dr. Janice Keefe is the advisor and an Associate Professor in the Department of Family Studies and Gerontology at Mount Saint Vincent University.

Shannon McEvenue
c/o Maritime Data Centre
Room 360 Evaristus Building
Mount Saint Vincent University
166 Bedford Hwy
Halifax, B3M 2J6
Telephone (902)420-1765

Dr. Janice Keefe
Associate Professor
Canada Research Chair in Aging and Caregiver Policy
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166 Bedford Hwy
Halifax, B3M 2J6
Telephone (902)457-6466

If you would like to speak to someone outside of the research project, you may contact the Mount Saint Vincent University Research Office:

Chair, University Ethics Review Committee
c/o MSVU Research Office
166 Bedford Hwy, EV 136
Halifax, Nova Scotia
B3M 2J6
(902) 456-6350

20. What Are My Rights?

After you have signed this consent form you will be given a copy.

If you have any questions about your rights as a research subject, contact the **Patient Representative** at **(902) 473-2133**.

In the next part you will be asked if you agree (consent) to join this study. If the answer is “yes”, you will need to sign the form.

Part C

21. Consent Form and Signatures
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I have read all the information about this study, which is called:

Palliative care in long-term care: Best practices in service delivery

I have been given the opportunity to discuss it. All my questions have been answered. I am satisfied with the answers.

I agree to allow the people described here to have access to my medical records.

This signature on this consent form means that I agree to take part in this study.

**Note: Please fill in the dates personally*

_____ Signature of Participant	_____ Name (Please print)	_____ Date
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_____ Signature of Witness	_____ Name (Please print)	_____ Date
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_____ Signature of Investigator	_____ Name (Please print)	_____ Date
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_____ Signature of Person Conducting	_____ Name (Please print)	_____ Date
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_____ Signature of Next of Kin (if req)	_____ Name (Please print)	_____ Date
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I Will Be Given A Signed Copy Of This Consent Form

Thank you for your time and patience!

Appendix D- Participant Observations

I. Participant Observation Plan

1. Meeting personal care worker or nurse
 - Personal care worker or nurse
 - General demeanor of worker
2. Start of Shift Preparations/Tasks
 - Briefing from previous shift
 - Daily tasks to prepare for shift
3. Before entering the resident's room
 - Comments regarding resident condition
 - Comments regarding resident demeanor or family life
 - Anticipation of problems
 - Specific instrumental tasks
4. Entering the room
 - How does worker greet resident?
 - General impression of resident's living space
5. Resident Care
 - Instrumental tasks
 - Response to resident requests or verbalized needs
 - Conversation and interaction between resident and worker
 - Overall demeanor of resident
 - Impression of comfort level of resident
6. Leaving the room
 - How does worker leave things with the resident once instrumental care tasks are completed?
 - Observed changes in resident or worker demeanor
 - Worker comments regarding individual care needs
7. Interaction with resident's and family outside of individual care
 - Care that takes place in hallways, common areas, family/relative rooms and outdoors

- Conversations/interaction that takes place outside of instrumental care
- Leisure and activities

8. Breaks

- Is worker able or willing to leave work behind during breaks?
- Are breaks affected by staffing issues?
- How do workers interact during breaks?
- What types of conversations take place?

9. Day End

- Debriefing/briefing of oncoming shift
- Shift end tasks
- Saying good-bye to residents

10. Death Event (Should this happen during observation)

- Reaction of worker
- Instrumental tasks
- Unit rituals
- Interaction with other residents immediately following a resident death

11. Coping

- Staff support groups?
- Interaction with residents and other staff
- End of the day- coping strategies/letting go of death and dying

II. *Observation Tool*

Observations will be made under the following categories:

1. **Resident and family focused** (sensitive to personal, cultural, and religious values, beliefs, and practices, their developmental state and preparedness to deal with the dying process)
2. **High Quality** (ethical, standards of practice based on nationally-accepted norms, policies and procedures based on best available evidence, data collection based on validated measures)
3. **Safe and Effective** (Collaborative, confidential, privacy, without coercion/harassment/judgement/prejudice, ensures safety and security, ensure accountability/continuity, minimization of duplication/repetition)
4. **Accessible** (equal access in a timely manner)
5. **Adequately resourced** (financial, human, information and physical resources)
6. **Collaborative** (uses available organizations and service partnerships)
7. **Knowledge-based** (ongoing education of all involved)
8. **Advocacy-based** (interaction with community to increase awareness)
9. **Research-based** (development, dissemination, and integration of new knowledge)
10. **Effective communication** (common language, standard protocols, collection of data that documents status, education of residents and families)
11. **Effective Group Function** (resident and family, careteam, regional teams, management team)
12. **Ability to facilitate change** (adaptability)
13. **Assessment** (information-gathering, history-taking, assessment tools)
14. **Information-sharing** (right to be informed, confidentiality, communication, language)
15. **Decision-making** (right to make informed decisions, consent, inclusion of family, assessment of decision-making capacity, prioritizing of goals, appropriate options, use of proxy, conflict resolution)
16. **Care planning** (respect choice/wishes, takes into account individual values and beliefs, customized and flexible, regular review)
17. **Care Delivery** (team approach, resources available, safe and timely, respectful, continuity, collaborative)
18. **Confirmation** (assessment or resident and family understanding and status)