Critical Nurse Behaviours

In The Care Of Dying Elderly Residents

In The Personal Care Home

By

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A Thesis submitted to the Faculty of Graduate Studies
In Partial Fulfillment of the Requirements for the Degree of

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Critical Nurse Behaviours In The Care Of Dying Elderly Residents In The Personal Care Home

ABSTRACT

Increased research attention is being directed toward expert nursing care of the dying. Research conducted to date in this area has delineated behaviours deemed critical in providing excellent end of life care in palliative care, intensive care, the community, and adult and pediatric medical units. Personal care homes (PCHs) are taking on an increasing role in caring for the dying. One impact of the baby boom generation and improved medical care is that PCHs will be the place of care and site of death for growing numbers of frail, older persons dying of chronic progressive illnesses. To date, however, critical nursing behaviours in the care of dying elderly residents in the PCH have not been examined. In order to redress this gap in the literature, a descriptive exploratory study was conducted with registered nurse experts (n=10) in two PCH settings. Thematic analysis of qualitative interviews conducted with the nurse participants in this study resulted in the generation of 10 critical nursing behaviours in care of the dying elderly in the PCH setting. The identification of these behaviours adds to extant knowledge regarding models of expert practice in care of the dying, and can be used to guide nursing education, practice, and research in this patient population.

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CHAPTER ONE

STATEMENT OF THE PROBLEM

Introduction

This chapter provides a statement of the problem for the current study, and outlines the study's purpose. Four research questions are posed. Assumptions underlying this research are identified and definitions of terms used throughout the study are provided. The final section of the chapter explains the significance of the study.

Statement of the Problem

The population in Canada has been aging dramatically (Fisher, Ross & MacLean, 2000). Currently, 13% of the Canadian population is aged 65 years and over, representing an increase of 10.2% since 1996 (Statistics Canada, 2002). Statistics Canada (2002) anticipates that the proportion of people aged 65 and over will start to increase more rapidly by 2011 when the oldest baby boomers, those born in 1946, reach age 65 years. In Manitoba, 14% of the population is aged 65 years and over, representing an increase of 2.8% since 1996 (Statistics Canada, 2002). Population projections in Manitoba suggest that the population aged 75 years and over will increase by 12% by 2020, relative to 2000 (Manitoba Centre for Health Policy, MCHP, 2004).

As the population ages, the need for institutionalization is likely to grow (Trottier, Martel, Houle, Berthelot & Legare, 2000). In 1995, 5% of the total Canadian population aged 65 years or older lived in personal care homes, with the proportion rising to 18% for those aged 80 or older (Tully & Mohl, 1995). In

Manitoba, there are currently 5,697 residents living in personal care homes (Winnipeg Regional Health Authority, WRHA, Personal Care Home Program Balanced Score Card, 2004). Statistics Canada's latest population projections suggest that the number of beds required in personal care homes nationally could rise from 184,000 in 1996/97 to over 565,000 in 2031 (Trottier et al., 2000). One impact of the baby boom generation and improved medical care is that nursing homes will be the place of care and site of death for growing numbers of frail, older persons dying of chronic progressive illnesses (Teno, 2003).

In Manitoba, while almost half (47%) of the deaths reported in the province between April 1, 2000 and March 2001 occurred in hospital, the largest proportion of deaths occurring outside hospital (24%) were in long-term care (MCHP, 2004). Furthermore, MCHP (2004) reported that most long-term residents (83%) died in a long-term care facility. Hanson (2003) stated that once someone becomes a resident of a nursing home, he or she is not likely to transfer to a hospital to die; two of three nursing home residents stay "at home" for their final illness and death.

The number of individuals who will die in a personal care home setting is likely to increase. According to Brock and Foley (1998), by 2040 nearly one in two persons in the United States will die in a nursing home. Nursing homes are taking on an increasing role in caring for the dying (Teno, 2003). Froggatt, Hasnip and Smith (2000) observed that a personal care home setting offers a unique environment where end of life care can be provided. Wilson (2001) stated that end of life care is clearly an important component of care in personal care homes, and that quality end of life care in this setting will become increasingly important as the number of older adults increases and managed care continues to minimize hospital stays.

Although personal care homes will continue to be a common setting for death (Ersek, Kraybill and Hansberry, 2000), Keay (2003) stated that nursing home residents' access to palliative care is – and may remain – restricted. The literature suggests several challenges to the provision of palliative care in the personal care home setting that may, in turn, "restrict" access to quality palliative care. First, prospectively defining a resident as dying is difficult for clinicians, and the unpredictability of a resident's health trajectory contributes to problems in planning care (Katz, Komaromy & Sidell, 1999). Personal care home staff and other supporting health care professionals are increasingly required to meet the needs of people designated as "dying" from time of admission, rather than caring for residents who live in personal care homes until they die (Froggatt, 2001).

Second, nursing home care emphasizes rehabilitation/ restorative care rather than excellence in end of life care (Ersek & Wilson, 2003; Porock, Oliver, Zweig, Rantz & Petroski, 2003; Reynolds, Henderson, Schulman & Hanson, 2002). As such, quality indicators for effective personal care home care (e.g. functional status, activity involvement, eating, and nutrition) may have little relevance to effective end of life care (Forbes, 2001). The goals of palliative care, such as reducing unnecessary interventions, minimizing symptom distress at the end of life, optimizing appropriate supportive interventions, and consultations are not currently captured in the quality indicators adopted by most facilities. Reynolds et al. (2002) stated that given the frequency of death in nursing homes, it is also appropriate to measure the quality of palliative care in these facilities. Relevant quality indicators are necessary if the impact of palliative care services are truly to be evaluated (Bookbinder, 2001).

Third, while registered nurses working in personal care homes have a critical role to play in providing skilled and sensitive end of life care, and can make significant contributions to enhance terminal residents' quality of life (Ersek et al., 2000; Hall, Schroder, & Weaver, 2002; Wilson, 2001), the literature suggests that most RNs feel unprepared to provide such care (Ersek et al., 2000). Goetschius (1997) asserted that nurses who provide end of life care in this type of setting must be as well-schooled in the appropriate interventions for dying residents as their colleagues in hospice nursing. Historically, however, nursing programs have typically not provided systematic education in the care of the dying (Degner & Gow, 1988; Irvine, 1993). Not surprisingly, nurses experience considerable anxiety when caring for terminally ill individuals without accompanying educational support (Copp, 1994; Degner, Gow & Thompson, 1991).

In an attempt to redress the dearth of empirical information examining nursing behaviours deemed to be critical in care of the dying patient, Degner and colleagues have conducted a series of qualitative studies that have generated an inductively derived list of "expert" nursing behaviours as they relate to the care of the dying in the palliative care unit (Degner, Gow & Thomson, 1991), adult intensive care (McClement & Degner, 1995), adult medical units (Harbeck, 1995), pediatric care (Hawkins, 1995), and the community/ home care (Helwer, 1994). The nature of such care has not been examined in a personal care home setting, however. Thus, the list of nurse behaviours generated to date (Table 1) is incomplete. This research study attempted to redress the gap that currently exists regarding the nature of expert nursing practice in care of the dying resident in a personal care home setting.

A wealth of untapped knowledge is embedded in the practice of clinicians who embody the art of nursing through expert practice (Hampton, 1994). Kennedy (1999) suggested that the holistic and personal nature of caring for patients with a terminal illness and their families requires more intuitive judgement than analytic logic (Kennedy, 1999). Intuitive judgement is what distinguishes expert human judgement from the decisions or computations that might be made by a beginner or by a machine (Benner & Tanner, 1987). The use of intuitive judgement is the distinctive practice of an expert nurse. Benner (1982) stated that at the expert level, the performer no longer relies on an analytical principle to connect her/ his understanding of the situation to an appropriate action. The expert nurse, with her/ his vast background of experience, has an intuitive grasp of the situation and zeros in on the accurate region of the problem without wasteful consideration of a large range of unfruitful possible problem situations (Benner, 1982). Hampton (1994) stated that observing nursing performance provides only minimal insight into why the expert nurse makes specific decisions. By assisting the expert to describe clinical situations where his or her interventions made a difference to patient and family care, some of the knowledge embedded in the expert's practice becomes visible (Benner, 1982).

Purpose of the Study

The overall purpose of this study was to describe the behaviours that registered nurse experts identify as critical to the care of dying elderly residents in the personal care home setting. The following research questions were addressed:

1. What are the behaviours that registered nurses in the personal care home deemed "expert" in care of the dying by their colleagues, describe as having a positive influence on the care of the dying elderly resident in the personal care home setting?
2. What are the behaviours that registered nurses in the personal care home deemed "expert" in care of the dying by their colleagues, describe as having a negative influence on the care of the dying elderly resident in the personal care home setting?
3. What factors do expert registered nurses identify as facilitating their ability to provide optimal care to the dying elderly resident in the personal care home setting?
4. What factors do expert registered nurses identify as constraining their ability to provide optimal care to the dying elderly resident in the personal care home setting?

Assumptions Underlying the Study

The following assumptions underlie this study:

1. There becomes a time when a curative treatment focus is no longer appropriate for a patient (Egan & Labyak, 2001).
2. The dying patient and their family are the unit of care in the provision of end of life care (Davies, 2001).
3. Bereaved families are at risk emotionally and physically (Corless, 2001).

4. Nurses should be able to demonstrate in-depth knowledge of grief and bereavement care and assist the family in the process of grief and bereavement (Canadian Hospice and Palliative Care Association, CHPCA, 2002).
5. Nurses have a pivotal role in the care of the dying in personal care homes (Wilson, 2001).
6. Emotional investment on the part of nursing staff is essential in the provision of effective end of life care (Vachon, 2001).
7. Expert nurses are able to reflect on their experiences in caring for the dying (Benner, 1982).

Definitions of Terms

The following terms are defined as they are used in this study:

Bereavement – the situation of anyone who has lost a person to whom he or she is attached (Parkes, 1998).

Elderly - individuals who are aged 65 years and older.

In the published literature, authors define the term "elderly" in several different ways. While some authors use the term to describe those individuals aged 60 years and older (Song & Lee, 1996), others have used the term "elderly" to describe individuals 65 years of age and older (Fahey, Montgomery, Barnes & Protheroe, 2003) and some even 75 years and older (Teno, Casey, Welch & Edgeman-Levitan, 2001). For the purposes of this study "elderly" will be used to describe individuals aged 65 years and older as it is anticipated that this will allow participants to focus their efforts on describing important aspects of the nurse's behaviours in end of life situations in personal care home settings rather than trying to recall whether the residents in the scenarios that they are describing were at least 75 years old.

End of Life Care – the provision of palliative care or terminal care to a resident in the last 4-6 weeks of life.

Throughout the literature "end of life" is defined in several ways. Some authors have used this terminology to describe a period of time as long as two years, when palliative care is provided to patients with chronic, life-threatening illness (Vachon, 2001), while others have used the term to describe the actual end of a person's life, or death (Byock, 2003). In this study end of life care will be defined as care provided to residents in the last 4 to 6 weeks of life.

Expert - the most knowledgeable member of a profession (Hampton, 1994).

Expert Nurse - The nurse who no longer relies on an analytical principle (rule, guideline, maxim) to connect an understanding of a situation to an appropriate action (Benner, 1982)

Experience - does not necessarily refer to longevity or length of time in a position; rather, it refers to a very active process of refining and changing preconceived theories, notions, and ideas when confronted with actual situations (Benner, 2001).

Expertise - a characteristic of individuals who have reached the pinnacle of performance in their discipline (Thompson, Ryan & Kitzman, 1990).

Family - includes not only persons bound by biology or legalities but also those whom the patient defines or who define themselves as a "close other" with another person, or those who function for the patient in "familistic" ways, such as nurturance, intimacy, and economic, social and psychological support in times of need, support in illness and companionship (Berry & Griffie, 2001).

Living-dying Interval - the period of time between the knowledge of one's impending death and death itself (Pattison, 1977).

Nurse - a person who has completed a diploma or baccalaureate nursing education program and who is registered as a registered nurse under the Registered Nurses Act of the College of Registered Nurses of Manitoba, CRNM (CRNM, 2001)

Palliative Care - "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patient care;

- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications." (World Health Organization, WHO, 2002).

Personal Care Home – a facility that provides residents with "personal care" in the nature of (a) basic nursing care under the supervision of a registered nurse, or (b) personal assistance in the a activities of daily living, or (c) supervision of activities of daily living, together with goods and services that are specified in provincial regulations as goods and services that are provided as part of personal care. This may include: meals, including special and therapeutic diets, routine medical and surgical supplies, prescribed drugs, and related preparations approved by the minister, routine laundry and linen services, and physiotherapy and occupational therapy in institutions approved by the minister for such services, and other goods and services approved by the minister (Government of Manitoba, 2002).

Personal Care Home Nurse – a registered nurse who is employed in a personal care home.

Resident – a person who lives in a personal care home (Government of Manitoba, 2002).

Significance of the Study

The purpose of this exploratory, descriptive study was to identify the critical nursing behaviours that expert nurses describe as central in the provision of end of life care to dying elderly residents in a personal care home. The hope was that research aimed at tapping the knowledge possessed by expert nurses who care for the dying elderly residents in personal care homes would allow for the description of critical nursing behaviours in the provision of end of life care to institutionalized elderly people. The generation of a typology of such behaviours would provide the basis for a model of expert care of the dying elderly in personal care homes, and help to build upon and extend the program of research undertaken by Degner and colleagues in the late 1980's aimed at identifying expert nursing practice in care of the dying. The generation of empirically derived behaviours could then be used to guide nursing education, practice, and research in this patient population.

Identification of the specific caregiving behaviours the nurse can do for dying patients and their families may also help to decrease a nurse's feelings of inadequacy, reduce the risk of the nurse withdrawing from the dying patient, and enhance quality care of the dying, and promote feelings of professional competence and job satisfaction.

Summary

Chapter one has outlined the statement of the problem as it relates to the issue of expert nursing behaviours in care of the dying in personal care homes. The overall purpose of the study has been identified, and specific research questions delineated. Assumptions underlying the study and definitions of terms as they relate to the project have been provided. The significance of the study has been discussed. The next chapter will provide a review of the literature salient to the study.

CHAPTER TWO

REVIEW OF THE LITERATURE

Introduction

The literature review presented here examines the current body of knowledge as it exists regarding care of the dying elderly in the personal care home setting, and provides a context within which to situate the study that was conducted. Five categories of literature were explored. These include: i) an overview of the definitions and philosophical underpinnings of palliative care; ii) a presentation of recent developments regarding the conceptualization of palliative care; iii) the appropriateness of the personal care home setting as an appropriate venue for the provision of palliative care; iv) factors contributing to the challenges of providing palliative care in the personal care home setting, and v) delineation of the role of the nurse in the provision of end of life care.

Palliative Care: Definition and Philosophical Underpinnings

The World Health Organization (WHO) provided a comprehensive definition outlining the philosophy, principles and goals of palliative care. The WHO (2002) defined palliative care as:

> " an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications." (WHO, 2002)

The above definition of the term palliative care provides the context for the type of care being examined in this proposed research study.

Palliative care is heralded as an approach to care that should be applied universally at the end of life. Ley (1989) stated that the philosophy of palliative care applies to all age groups, and Maddocks (1996) affirmed that palliative care principles should be understood and implemented by all health professionals wherever their patients are receiving terminal care. Jones and Faulkner (1996) acknowledged that palliative care may be delivered in a variety of settings from acute hospitals and hospices, through nursing homes and residential units, to patients' own homes.

Recent statistics on illness at the later stage of life suggest that a large number of seniors will need end-of-life care (Fisher et al., 2000). However, the continuing care of patients cannot be the sole responsibility of palliative care specialists (Addington-Hall, 1998), as few palliative care/ hospice units are able to allocate beds for long-stay care (Maccabee, 1994). This means that older people who require palliative care will increasingly need to be supported at their place of residence within the community, in their own home or a nursing home (Froggatt, 2001).

Palliative care has been acknowledged as an important component of nursing home care (Wilson, 2001). The nursing home, or personal care home as is the term more commonly used in Manitoba, has been recognized in the literature as a setting where the provision of quality palliative care is essential. Parker and De Bellis (1999) stated that because palliative care focuses on communication with the patient and the family, and emphasises psychosocial care alongside physical care, it addresses many of the problems identified with care of older people in personal care homes with a terminal illness. Palliative care thus provides an excellent model for care of those who are dying, many of whom may be suffering from dementia (Parker & De Bellis, 1999).

Despite seemingly obvious reasons why the provision of palliative care is important in the personal care home setting, extant literature contends that this particular environment may not be conducive to the provision of this type of specialist care. Fisher et al. (2000) has indicated that the emphasis on end-of-life care has tended to focus on the needs of younger people with cancer or Human Immunodeficiency Virus (HIV)/ Acquired Immunodeficiency Syndrome (AIDS) and not on the needs of seniors. Therefore, it cannot be assumed that the dying promoted within a palliative care model is appropriate for, or desired by, all older people (Froggatt, 2001). The next section of this chapter explores the personal care home setting as an important setting for the provision of palliative care, followed by a presentation of the challenges identified in the literature to the provision of such care in this environment.

Developments to the Concept of Palliative Care

While palliative care has traditionally been thought of as an approach to care that begins at the time when active treatment aimed at curing the disease or prolonging life has ceased to be effective (Vachon, 2001), the term palliative care has since developed several new meanings. In the literature, palliative care has been referred to as "supportive care" or "comfort care" that seeks to prevent, relieve, alleviate, lessen, or soothe the symptoms of disease without effecting a cure (Bookbinder, 2001). Furthermore, the term "hospice" has sometimes been used interchangeably with the term palliative care, but more recently the terms have come to have different meanings. For example, in the United Kingdom, a hospice is a building where dying persons are cared for, but many of these people are discharged home and followed by home care teams (Doyle, Hanks & MacDonald, 1998). In Canada, hospices are often community-based, volunteer-driven programs providing care in the home (Vachon, 2001). In the United States, the term hospice has yet another definition and refers to a specific programmatic model for delivering palliative care. (Vachon, 2001).

In the clinical context, palliative care is seen as active and compassionate care directed primarily toward symptom management and improving the quality of life for the patient and family (Pasacreta, Minarik & Nield-Anderson, 2001). The term refers to the attempt to provide care that recognizes the need for the comprehensive management of the physical, psychological, social, spiritual, and existential needs of patients and families facing incurable, progressive illnesses (Vachon, 2001). Since palliation can be defined as the process of alleviating symptoms without curing, some see palliative care as extending across the illness continuum (Doyle et al., 1998). Therefore, palliative care is not reserved for the period of terminal care as is often believed (Pasacreta et al., 2001).

According to Kemp (1999), the last days and hours of life are supremely challenging because physical, psychosocial, and spiritual issues are often magnified, and the intensity of all aspects of care increases. Furthermore, as death nears, the goals of care must be discussed and, as appropriate, redefined (Berry & Griffie, 2001). Berry and Griffie (2001) stated that issues and needs at the time of death are exceedingly important and, at the same time, exceedingly personal:

> "While the physiology of dying may be the same for most expected deaths, the psychological, spiritual, cultural, and family issues are as unique and varied as the patients and families themselves" (p. 382).

In an attempt to more clearly delineate between the general transition from curative treatment to the subsequent focus on symptom management from the actual point of uncompromising, advanced illness that includes the death event, new terminology has emerged. Terms such as "terminal care" and "end of life care" are increasingly being used to isolate the final period of a dying patient's life. It should be noted however that there are inconsistencies in the literature about the meanings of these new terms as well. For example, end of life care was defined by one author as extending the concept of palliative care to patients with chronic, life-threatening illness who may have one to two years to live. (Vachon, 2001). Others have used the term to describe the actual end of a person's life, or death (Byock, 2003). In order to focus this research study on the specific nursing behaviours critical in caring for dying residents in the personal care home, the term "end of life care" will be used to refer to the provision of palliative care, as defined by the WHO (2002), in the last four to six weeks of an elderly resident's life.

The Personal Care Home Setting:

Globally, we have a population that is ageing (Cohen, O'Connor & Blackmore, 2002). According to Wilson (2001), death occurs more frequently among older adults in institutions than at home among family and friends. There is a general consensus in the literature that personal care homes provide a care environment for the long-term care of older people, usually until their death (Addington-Hall, 1998; Ersek et al., 2000; Froggatt, 2001; Froggatt et al., 2000; Miller and Mor, 2002; Teno, 2002; Zerzan, Stearns & Hanson, 2000). The older people are, therefore, the more likely they will die in personal care homes (Wilson, 2001). Teno (2002) contends that the impact of the "baby boom" generation and improved medical care explain why personal care homes will be the place of care and site of death for growing numbers of frail, older persons dying of chronic, progressive illnesses.

Unlike individuals who die in hospital or hospice settings, residents who die in a personal care setting are, in essence, dying in their own home (Hanson, Henderson & Menon, 2002; Wilson & Daley 1999). For this reason, the personal care home setting would appear to be an appropriate environment wherein residents could receive palliative care. Indeed the provision of quality palliative care in personal care homes will become more important as the number of older adults increases and managed care continues to minimize hospital stays (Wilson, 2001). Despite the fact that so many people die in nursing homes, there is minimal empirical work examining the experience of death and dying from the perspectives of residents, family or health care providers in personal care homes (Hanson et al., 2002; Kayser-Jones, 2000).

Despite the paucity of empirical work examining the experience of death and dying in this environment, anecdotal literature suggests that personal care homes are appropriate places for the provision of palliative care for dying elderly residents for three reasons. First, personal care homes have been likened to "heaven's waiting room" (Forbes, 2001). Growth in the numbers of residents who live in personal care homes has been proportionate with the increasingly elderly population, and the need for long-term care services will continue to increase as the population ages (Wilson, 2001). This need for longer-term care sometimes requires advanced cancer patients and their families to make decisions about transfer to a personal care home

(Maccabee, 1994). According to Froggatt (2001), this is acceptable because personal care homes lie at the interface between continuing care for older people and palliative care.

Secondly, personal care homes are appropriate places for the provision of palliative care for dying elderly residents because of the willingness of staff to try and incorporate the principles of palliative care in the care milieu, and the home-like atmosphere that staff attempt to create for residents. Katz et al. (1999) reported the findings from their large-scale study that investigated the quality of care provided for those dying in residential and personal care homes in England. A multi-method approach was used to collect data from residential, nursing and dual-registered homes (n = 1000) in England and included a postal survey, interviews with home managers (n = 100) and case studies with a sample of the homes (n = 12). The authors reported the extent to which home managers, care staff and general practitioners understood and operationalized palliative care concepts and concluded that all categories of personal care home staff shared understandings of what constituted a "good death." While it was also demonstrated that most homes were constrained by factors including the lack of support from their own physicians as well as specialist palliative care services when caring for dying residents, the study identified a willingness on the part of all categories of staff to care for residents until death, with many homes aspiring to provide dying residents with good terminal care.

Similar results were found in a pilot-project conducted by Avis, Greening Jackson, Cox and Miskella (1999) that evaluated a pilot community care project to extend hospice standards of palliative care to nursing home residents in Nottingham.

The evaluation included two questionnaire surveys of all matrons of nursing homes with registered palliative care beds, and 35 interviews with a sample of local stakeholders selected to give a range of views of the project's impact. The project was a 3-year endeavour that involved an assessment of the services required by nursing homes within the framework of the project's specifications. A nurse advisor/ coordinator and a peer support group of six district nurses then implemented the project that included providing advice to nursing home staff concerning individual care problems; providing training and support for staff on the principles of palliative care, pain and symptom management, addressing resources and improving communication with other professionals, and: offering support and advice for residents and relatives including bereavement counselling and psychological support. While the selection of residents and families who participated in the interview portion of the evaluation was guided by the project coordinator who implemented the project, the researchers minimized the effects of bias by limiting the numbers in that group (n = 4). Avis et al. (1999) reported that respondents generally accepted that personal care homes provided an appropriate standard of palliative care where the informal, home-like atmosphere was well-suited to the care of dying residents, and that this setting would become more important in the overall provision of palliative care because of the increasing number of dying elderly residents to be cared for.

The importance of nursing homes being able to provide palliative care to its residents within a home-like setting is echoed by Ley (1989) who asserts that elderly people are less concerned with the time left to live than with the quality of that life. This perspective is in keeping with Engle's (1998) notion that the personal care home setting and staffing patterns necessitate effective, non-invasive interventions with minimal side effects that are low cost, low tech, and low labour. Engle (1998) stated that such "added value" interventions promote comfort during the living-dying interval.

Third, personal care homes are appropriate places for the provision of palliative care for dying elderly residents because of the emotional attachment that tends to develop between residents and their long-term care providers. A length of a resident's stay in a personal care home improves the staff's abilities to individualize the care provided to a particular resident. Individualized care is embedded in personal and longitudinal relationships with residents made possible by the unique combination of housing and health care on site (Hanson et al., 2002).

Hanson et al. (2002) contend that the opportunity for longitudinal relationships is a unique asset of nursing home care, impossible in hospital or hospice with short lengths of stay. The continuity of caring relationships between residents and nursing home staff members may be a compelling strength of this setting (Hanson, 2003). These close relationships allow staff to detect subtle clues that occur during the course of terminal illness, and long-term daily contact also may promote knowledge and understanding regarding residents' values, personal goals and care preferences (Ersek & Wilson, 2003).

The literature supports that residents spend considerable time in personal care home settings prior to their death, during which attachment to health care providers may occur. In a study conducted by Reynolds et al. (2002) designed to describe the symptoms and palliative needs of North Carolina nursing home residents during the last three months of life, the authors found the 39% of the residents in their study had lived in the nursing home for more than one year. The current length of stay in Winnipeg personal care home facilities is 2.69 years (WRHA, 2004).

Residents may also become attached to others who also live in the personal care home setting. Wilson and Daley (1999) observe that personal care facilities are home for many people, and residents come to consider other residents and family members as a surrogate family. In fact, the term "family" could describe all those living and working within the personal care home (Froggatt et al., 2000).

Ersek et al. (2000) conducted a qualitative study to explore and describe the education needs and concerns of licensed nursing staff and certified nursing assistants regarding end of life care. Data were collected using focus group interviews with staff (n = 39) from two nursing homes in the Pacific Northwest. Participants reported that they too saw themselves as family to the residents, a phenomenon that enhanced care but also caused great stress for them when residents died. The major issue voiced by personal care home staff in this study was their attachment to residents and the factors that influenced attachment and quality of care. Ersek et al. (2000) stated that attachment was the strong emotional bond that developed between staff and residents, causing staff to view themselves as surrogate family to residents. The process of attachment is influenced by individual mediating forces, including caring and presence, knowledge and communication (Wilson & Daley, 1998).

Wilson and Daley (1998) conducted a study in Wisconsin to describe staff and administrators' perspectives on death and dying in long-term care, and to explore problems in providing humane care to dying residents that fosters a gentle closure to life. Twenty-two focus group sessions were conducted with 155 participants from 11 nursing homes. The researchers reported that the core variable identified was the attachment of staff to residents and they proposed that attachment of care providers to residents enhances the quality of terminal care residents receive, and fosters a gentle closure to life. Despite this claim, the authors did not provide an explanation of how this transpired. Wilson and Daley (1998) stated that attachment is fostered by staff's efforts to care for residents and in some cases be their "family". The authors suggested a model to illustrate the way that mediating forces (classified as individual care provider forces, forces internal to the care home and forces external to the care home) influence attachment. The attachment that developed between nursing home families and staff was also identified as helpful to family members in coping with the loss of a loved one (Wilson & Daley, 1999).

Despite the identified positive effects of attachment between staff and residents, it should be noted that some authors indicated that attachment can lead to increased feelings of loss and sadness on the part of staff when a resident dies (Ersek et al., 2000; Wilson & Daley, 1998). Hanson (2003) however, stated that the best nursing home nurses and nursing assistants become like a family and that their relationships may provide comfort during the dying experience. Furthermore, although nursing home staff acknowledged that close bonds with residents caused them to grieve after each death, they valued the highly individualized care they were able to provide as an essential in good care for dying residents (Hanson et al., 2002).

While there is literature suggesting that that personal care homes "are an optimum site for palliative care" (Carter & Chichin, 2003 p.357), Travis, Loving, McClanahan and Bernard (2001) contend that neither the term “palliative care” nor the associated approaches to providing such care have been well integrated into most personal care home facilities. Rather, they state that the barriers to fully implementing high-quality, comprehensive palliation in this setting are better documented in the literature than are reports of successful end-of-life programs (Travis et al., 2001). The next section outlines what has been documented in the literature about the provision of palliative care being perceived as problematic for personal care homes.

The Challenge Of Providing Palliative Care In The Personal Care Home:

Although personal care homes are a common setting for death, the literature suggests that providing end of life care in this environment is challenging for health care providers working in this setting (Ersek et al., 2000). The next section presents factors identified in the literature as posing challenges for personal care homes in the provision of palliative care. The information has been classified and presented as “external factors” (those challenges that originate outside of the personal care home environment and which are beyond this setting’s control) and “internal factors” (those challenges that originate within the personal care home environment over which the setting may have some degree of influence).

External Factors

Several external factors are identified in the literature which pose problems for the provision of palliative care in the personal care home setting. These factors relate to the nature of the residents receiving care in this environment and includes the changing profile of individuals admitted to personal care homes, as well as the primary diagnoses, symptoms and disease trajectories of the illnesses experienced by residents who live in such homes.

Profile of Personal Care Home Residents:

The growing number of older adults living with multiple chronic illnesses coupled with changes in the delivery of acute care (shortened hospital stays) is changing the complexion of the personal care home population (Forbes, 2001). In the past, the "typical" nursing home resident could be characterized as: i) unable to be self-supporting and requiring assistance for activities of daily living; and ii) entering the personal care home environment where the focus of care was primarily on care of the living and attainment of one's maximum capability whatever the age. Maddocks (1996) reports that individuals being admitted into personal care homes today are more frail, more demented and more terminal than was formerly the case. The aging population already in care has become increasingly frail, and older people are entering personal care homes at a stage when they require extensive care (Komaromy, Sidell & Katz, 2000). This is consistent with Nolan and Davies' (2000) observation that the population within care homes is changing with there now being far higher levels of physical and cognitive disabilities. Forbes (2001) reported similar findings regarding the nature of residents receiving care, and suggested that increased frailty could be attributed to the numerous co-morbid conditions with which residents present.

According to Stein (2001), this trend, which the author referred to as "sicker and quicker", has resulted in personal care home residents requiring a higher intensity of care. Wilson (2001) also suggests that the intensity of care required by residents has increased because more people enter nursing homes as a result of early hospital discharge. Furthermore, in the previously mentioned study by Avis et al. (1999), personal care home staff identified that patients admitted to personal care homes were becoming more dependent and they expressed concern about the rising numbers of patients being admitted in the later stages of a terminal illness. This caused problems for patients and their relatives in adjusting to a new environment at a particularly stressful time and for the personal care home in trying to assess and care for the patient (Avis et al., 1999).

The increased severity of patients in personal care homes affects the care that is provided by staff because the principal characteristic of dying residents who require palliative care is one of high dependence. Such dependence entails an increase in nursing and personal care, and therefore an overall increase in the use of resources (Parker & De Bellis, 1999; Wilson & Daley, 1998). Moreover, residents of personal care homes are often aware of the death of other residents. This loss is acknowledged as stressful for other nursing home residents (Wilson, 2001) as well as their family members (Wilson & Daley, 1998). In addition to the attention required by the deceased residents grieving family, the provision of bereavement care to the other individuals in the personal care home also impacts on the available human resources in this setting. According to Froggatt et al. (2000), changes in the funding of hospice contracts and use of their facilities, in addition to increased pressures on acute hospital beds, mean that more older patients in terminal phases of cancer and other diseases are being discharged from hospitals and hospices directly to personal care homes for care until they die.

In a study by Porock et al. (2003), the prevalence, profile, and survivorship of residents admitted to long-term care facilities were described using the Minimum Data Set (MDS) designation of being at the end of life. Variables for analysis were selected from the MDS items that are clinically relevant for those residents at the end of life: pain, incontinence, skin condition, activities of daily living, depression and weight loss. In addition, the authors selected items regarding advance directives, use of special treatments, and diagnoses because they were deemed important to the care of residents at the end of life (Porock et al., 2003). While the analysis was limited to residents in long-term care facilities that were known to have hospice contracts (n = 159) this study reported that the majority of new residents to these long-term care facilities were admitted from acute hospital settings and 4.5% of admissions to long-term facilities met the end of life definition. Such research demonstrates that the profiles of residents in nursing home settings have changed. Nursing homes must now provide care for persons admitted under a range of circumstances. These may include recently hospitalized persons needing short-term rehabilitation; frail persons (many with cognitive impairments needing custodial and skilled nursing care) and dying, frail older persons who lack caregiver(s) or whose caregiver(s) cannot meet their needs for care (Teno, 2003).

Terminal Diagnoses in Personal Care Home Residents: More Than Just Cancer

According to Ley (1989), palliative care was developed for people dying from cancer. For seniors, end of life may be associated with cancer. According to Fisher et al. (2000), the majority of new cancers are found in persons over the age of 60 years. Not surprisingly however, given the focus on cancer care, there has been relatively little research into the experiences of people dying from other conditions (Addington-Hall, 1998), particularly in elderly people. In fact, the focus on a particular diagnosis may have created an underclass of dying people who do not get access to specialist care (Harris, 1990). It has been stated that the process of dying experienced by many residents of personal care homes is different than that experienced by people dying from cancer (Engle, 1998; Froggatt et al., 2000). In fact, it appears that palliative care as derived from a cancer care model is not necessarily applicable or appropriate for all residents dying in personal care homes from other causes.

Ample evidence demonstrates that cancer is not the only cause of death that results in considerable distress in the final months of life for both patients and families (Addington-Hall, 1998). In Canada, the leading cause of death in adults 65 years of age or more is heart disease, followed by cancer, stroke and respiratory disease (Fisher et al., 2002). Casarett, Hirschman and Henry (2001) conducted a study to explore the possible benefits and challenges of hospice involvement in nursing home care by comparing the survival and needs for palliative care of hospice patients in long-term care facilities with those living in the community. The researchers used a retrospective review of computerized clinical care records to compare patients who were admitted to a hospice from personal care homes to patients admitted from the community. The researchers concluded that personal care home residents had different admitting diagnoses - most notably a lower prevalence of cancer (Casarett et al., 2001). According to Fisher et al. (2000), while some residents in personal care homes die from malignant disease, many die from congestive heart failure, chronic obstructive pulmonary disease, stroke, and complications of dementing illness. Hanson (2003) reported that nursing home residents are more likely to die from chronic neurologic, cardiac or pulmonary diseases and less likely to die from cancer than persons who die at home or in hospitals. Reynolds et al. (2002) conducted a study to describe the prevalence of symptoms and palliative care needs of dying nursing home residents during the last 3 months of life. The researchers completed structured interviews with nurses, certified nursing assistants, and family members after all deaths of residents who died in two nursing facilities over a 1-year period. For each resident who died, family and staff caregivers answered parallel questions on the presence of physical and emotional symptoms, unmet needs for treatment of those symptoms, and the quality of the dying experience. The researchers reported that the most frequent causes of death were pneumonia (19%), coronary artery disease (19%), congestive heart failure (19%), cancer (17%) and stroke (10%).

That residents frequently die from causes other than cancer may pose a problem for personal care homes who attempt to follow the guiding principles of palliative care. For example, the care of persons with end-stage dementia differs from the care of persons with end-stage cancer in that the course of cancer is more predictable (Kovach, Wilson & Noonan, 2000; Wilson, 2001). Furthermore, problems often experienced by persons with cancer (such as pain, nausea, vomiting, and breathing) are less common in those with dementia (Wilson, 2001). Moreover, end stage dementia care differs from the care of end stage cancer patients because end stage dementia residents generally cannot communicate their needs or wishes and use much less narcotic analgesia (Kovach et al., 2000). More will be presented on the differences between symptoms and disease trajectories of residents dying in personal care homes in the sections following. However, the difficulties in caring for elderly patients with chronic, mostly non-cancer, diseases should be noted. Although less than 15% of older people in care homes die of a terminal disease such as cancer, many more die following a period of slow deterioration (Goodman, Woolley & Knight, 2003). According to Hanson et al. (2002) the challenge lies in the fact that the slow trajectory toward death for these patients was often punctuated by acute and apparently reversible illnesses such as pneumonia, sepsis and dehydration. Furthermore, episodes of acute illness might occur repeatedly prior to death (Hanson et al., 2002). In addition, reliable information describing end of life care in personal care homes, where chronically ill, functionally impaired older adults are the majority of the personal care home population, is largely unavailable (Engle, 1998). Few researchers have studied care at the end of life for those with chronic illness diagnoses in long-term care settings, particularly nursing homes (Forbes, 2001). This may be due in part because for the majority of nursing home residents, death is an inevitable outcome and most will die without a terminal diagnosis (Forbes, 2001).

The medical management of terminally ill elderly patients is also complicated by their age and the frequent presence of multiple medical problems (Ley, 1989). It has been stated that when treating the older adult in palliative care, the potential for confounding pathology as a result of the patient's age cannot be ignored (Matzo & Witt Sherman, 2001). Hall et al. (2002), using a convenience sample of 5 long-term care facilities, completed a chart audit of 185 charts using an audit tool developed for the study that focused on the symptoms and issues that arise in end of life care. The researchers were focused on the last 48 hours of life of dying residents and reported that 53% of residents had three or more symptoms (Hall et al., 2002). According to Ley (1989), the presence of multiple pathologies and a multiplicity of symptoms in elderly people frequently makes dying a diagnosis of exclusion and severely limits the time available to provide good palliative care. It could be argued that persons aged 75 years and over, are slowly dying and thus merit palliative care for some longer period of time before their demise (Ley, 1989). This begs the question of when and where to initiate such care, and how and by whom it should be carried out (Ley, 1989).

Symptoms

It is often very difficult to discern whether symptoms experienced by elderly residents at the end of life are due to depression, various treatment modalities, or advancing chronic illnesses (Matzo & Witt Sherman, 2001). According to Matzo and Witt Sherman (2001), the conventional wisdom is that, because a person is of advanced age, symptoms normally amenable to palliative care are just normal consequences of aging. Therefore, it is not uncommon for the primary health care provider to care for a dying older adult who does not report symptoms of weakness, fatigue, pain, or anorexia simply because many older patients erroneously consider these symptoms to be inevitable signs of aging, and not as problems to be treated

(Matzo & Witt Sherman, 2001). In addition, many residents experience a significant degree of cognitive impairment in the personal care home. The findings of the chart audit completed by Hall et al. (2002) reported that 51% of residents experienced cognitive impairment in the last 48 hours of life. This is consistent with a larger report that indicates that in Canada, 50% of people with dementia live in institutions (Fisher et al., 2000). These data have implications regarding the assessment of symptoms because this condition may make verbal reporting by residents problematic (Hall et al., 2002).

Relatively little research attention has been given to the prevalence of symptoms in seniors who are dying (Ross et al., 2000). The small number of studies examining the types of symptoms and their prevalence in terminally ill residents of personal care homes report conflicting findings. For example, Reynolds et al. (2002) stated that the most common physical symptom experienced by dying residents in nursing homes was pain. Pain was followed by problems with personal cleanliness, dyspnea, incontinence and fatigue (Reynolds et al., 2002). Ley (1989) reported however, that shortness of breath, restlessness, and agitation are the more common symptoms in dying elderly people than pain. Ley's findings were echoed by Casarett et al. (2001) who also found that several symptoms requiring palliation were less common among nursing home residents, including constipation, pain and anticipatory grief. In addition, Hall et al. (2002) reported that dyspnea was the most prevalent symptom in their study. Some of the discrepancies in the reporting of the most common symptoms at the end of life in personal care homes may be attributed to the timing of the research. For example, Hall et al. (2002) focused on the last 48 hours of life in dying elderly residents, whereas Reynolds et al. (2002) described the palliative care needs of dying nursing home residents during the last 3 months of life. Ley (1989) did not specify the time frame in her report. Nonetheless, because the majority of residents who die in personal care homes do so from non-malignant disease, one might be tempted to deduce that assessment of pain (reported by Addington-Hall (1998) to be the most common symptom reported by individuals diagnosed with cancer and in the last year of life), should not be a primary concern to personal care home nurses. Addington-Hall (1998) reported however, that patients with heart disease (previously identified as one of the most common causes of death in residents of personal care homes) were as likely as patients diagnosed with cancer to have had pain the last week of life. Furthermore, Wilson (2001) reported however, that pain is often untreated in the nursing home population. Parker and De Bellis (1999) conducted a study to describe the profile of 45 residents in 10 South Australian nursing homes who were identified as dying by nursing home staff. Residents experienced a total of 17 symptoms, with pain identified as one of the most common and severe. In addition to pain, there was conflicting information about the prevalence of constipation in personal care home residents. Whereas Addington-Hall (1998) stated that constipation is more prevalent in cancer patients, which was consistent with Casarett et al. (2001) who reported that constipation was less common among personal care home residents, the study of symptoms most common and severe in residents of personal care homes (Parker & De Bellis, 1999) identified constipation as one of the top four.

Conflicting information from the literature regarding the most common symptoms experienced by people who are dying is likely due to several factors. While some researchers compare symptoms experienced by patients dying of cancer with those experienced by patients dying from non-malignant diseases, others report the differences in the symptoms experienced by patients dying across different care settings. Varying definitions of the period of time referred to as "dying" or "end of life" are also used resulting in some studies covering more or less of the time before a patient's actual death.

In addition to the limited and conflicting literature about the symptoms experienced by dying residents in personal care homes, the management of symptoms, particularly pain, pose another challenge in the provision of quality palliative care in this setting. According to Froggatt et al. (2000), the principle of pain control can be used as an example of the difficulties inherent in transferring and translating the palliative care principles into a setting such as a personal care home. This is because patients in a nursing home may well receive regular analgesics for chronic pain, but the pain picture can be complex due to sporadic and episodic changes that do not necessarily equate with marked deterioration or disease progression (Froggatt et al., 2000). Furthermore, Froggatt et al. (2000) stated that pain may have multiple causes, and not be related to a specific diagnosis. Consequently, the accepted approach to pain management through the use of validated tools becomes of limited value to personal care home staff (Froggatt et al., 2000). In addition to these issues, the use of narcotics or other drugs to control symptoms is modified by their interaction with coexisting medication and by the changes in drug metabolism that accompany age (Ley, 1989). Pain management is further complicated by the large number of cognitively impaired residents who are verbally unable to articulate their experience of pain to health care providers (Wilson, 2001).

Disease Trajectories

"Disease trajectory" is a term used to describe the progression or worsening of a disease over time. This concept is most often used for chronic and incurable diseases where the stage of the disease is an important determinant of therapy and prognosis (Online Medical Dictionary, 2003). Although doctors and nurses are less accurate in predicting life expectancy in cancer patients than sometimes thought, it is generally accepted that it is more difficult to judge the likely time that patients have left to live who have a non-malignant disease (Addington-Hall, 1998). The nature of dying in older people has been recognised as very different from the trajectory experienced by people dying of cancer (Froggatt et al., 2000). The dying trajectory of older people who have chronic health concerns is often characterized by a lack of certainty (Field and James, 1993), largely because of the absence of a significant event (such as blood chemistry changes, or an obvious and pronounced decrease in activity tolerance) signalling that the illness has entered its terminal phase (Komaromy et al., 2000). Katz et al. (1999) state that in order to plan the delivery of palliative care, it is first necessary to define a person as dying. Personal care home managers in the study conducted by Katz et al. (1999) found it difficult to pinpoint the beginning of the terminal phase of illness in residents and classified their residents as chronically ill and likely to die at any time. Defining a resident as "dying" was difficult prospectively and the unpredictability of a resident's health trajectory contributed to problems in planning care, which included constructing a plan of action and often included notifying relatives and the physician (Katz et al., 1999). Personal care home staff are challenged with providing care for residents with diseases that have trajectories of slow decline with periodic crises and less-defined terminal phases (Hall et al., 2002). The chronic illness trajectory disguises the dying process (Forbes, 2001). The complexity of the care needs of nursing home residents and the uncertainties inherent in these people's dying trajectories means that it may not necessarily be appropriate to use the model of dying developed for people with cancer for people who live with different disease trajectories (Froggatt, 2001). Conversely however, Addington-Hall (1998) stated that the experience of palliative care services already accepting patients with non-malignant diseases suggests that services do not necessarily receive an overwhelming number of referrals, and that difficulties in judging life expectancy do not inevitably cause problems.

According to Forbes (2001), little is known about the needs and outcomes of care for those dying from chronic illnesses that have more variable disease trajectories. However, there appears to be wide range of opinions of the projected life-spans of residents in personal care homes. Some of the literature indicates that residents may live for several years. According to Wilson and Daley (1998), personal care home residents may survive months or years with a chronic illness before death. Travis et al. (2001) stated that blended care (active treatment with palliation) may last for years with relatively short periods dedicated solely to palliation. These particulars on illness at the later stage of life suggest that a large number of seniors will need end-of-life care over a significant period of time. This can pose a problem for personal care homes accessing palliative care resources because in many palliative care programs, the time limit of care is less than 90 days and such programs usually target cancer patients (Fisher et al., 2000).

The literature also identifies that personal care home residents' survival is significantly shorter than that of terminally ill individuals living in the community (Casarett et al., 2001). An increasing number of residents are admitted for a much shorter time, sometimes dying within days or hours of admission (Parker and DeBillis, 1999; Wilson & Daley, 1998). This suggests that a significant number of residents require terminal care from time of admission (Froggatt et al., 2000; Parker and De Bellis, 1999). In the literature, it is acknowledged that the projected life-span for residents in personal care homes cannot be predicted. Death may occur within a short period following admission to a personal care home or it may occur after many years of chronic disease (Parker & De Bellis, 1999). Parker and De Bellis (1999) stated that disease trajectory in personal care homes is really of little consequence because the length of time spent in a nursing home before death may not be indicative of the amount of care required by a resident as death approaches. Nonetheless, nursing home staff and other supporting health care professionals are increasingly required to meet the needs of people designated as "dying" from admission, rather than caring for residents who live in personal care homes until they die (Froggatt, 2001). Pattison (1977) suggested that rather than continue to focus solely on end of life care during the last few weeks of life, a shift is needed to focus on the chronic living-dying interval. The living-dying interval was defined as the period of time between the knowledge of one's impending death and death itself (Pattison, 1977). Maddocks (1996) stated that the challenge for personal care homes will be to find a mechanism for identifying the relatively small number of residents who need skilled palliative care. According to Engle (1998), it may be necessary to consider all permanently-placed personal care home residents as being in the chronic living-dying interval.

Internal Factors

Internal factors are those challenges to the provision of palliative care that originate within and by the personal care home environment, and which the setting may influence to some degree. Several internal factors are identified in the literature. They include: i) lack of knowledge about the principles and practices of palliative care; ii) care provider attitudes/ beliefs; iii) staffing levels and lack of available time for dying residents; iv) lack of physician support; v) lack of privacy for residents and families; vi) families' expectations; and vii) hospitalization of dying residents.

Lack of Knowledge About Palliative Care

Personal care home settings will increasingly need to expand the level of end of life care that they currently provide. Katz et al. (1999) investigation regarding the quality of care provided for those dying in residential and personal care homes in England identified that personal care home staff shared a common understanding of what constituted a "good" death. It was also identified that there was a willingness on the part of all categories of to care for residents until death. Despite this apparent good will, however, the literature suggests that other than nursing home managers, few members of staff, understood what was meant by the term "palliative care" (Katz et al., 1999), and even among managers this level of understanding was inconsistent (Komaromy et al., 2000). In their study investigating the management of death and dying in residential and personal care homes for older people Komaromy et al. (2000), only 34% of personal care home managers sampled (n = 100) were familiar with the hospice philosophy and only 15 individual personal care home managers had a detailed understanding.

In addition to nursing home managers, the literature also suggests that the level of understanding regarding the principles of palliative care is variable among staff. Avis et al. (1999) in their study that evaluated a pilot community care project to extend hospice standards of palliative care to nursing home residents in Nottingham reported that while some staff had up-to-date knowledge of the principles and practice of palliative care, others were 'out of touch.' Unfamiliarity with the philosophy of palliative care and a lack of understanding of the goals in the care of the dying was also reflected in a commentary by Engle (1998) who described the reconceptualization required by personal care home staff to provide hospice-type care for all permanently placed personal care home residents. For example, Engle (1998) stated that while residents are the best source of pain information, they are not asked to evaluate their own pain even when they were able to do so. Failure to access such information from care recipients themselves is inconsistent with the philosophy of palliative care to promote autonomy and dignity by enhancing function and independence as much as possible (Michael, 2001).

While it was widely agreed that the personal care home is an appropriate setting for palliative care, concern was also expressed throughout the literature about the quality of care that can be provided in a setting that relies almost exclusively on the common sense of care staff who are unlikely to receive any training in meeting the needs of dying people (Avis et al., 1999). According to Ersek et al. (2000), despite the increasing need for the provision of skilled end of life care, nursing home staff members often are unprepared to assume this important role. Few staff working in personal care homes received dedicated training in terminal care (Katz et al., 1999). Raudonis, Kyba and Kinsey (2002) conducted a study of 164 licensed nurses from 24 long-term care facilities in north central Texas and found deficiencies in their knowledge of palliative care. Specifically, the researchers reported that findings of their study demonstrated that nurses employed in long-term care need information about pain and symptom management and information about the philosophy and principles of palliative care. This supports the conclusion that personal care homes rely almost exclusively on the common sense of unqualified care staff who were unlikely to have received any training for the provision of hands-on care to meet the needs of dying residents (Avis et al., 1999; Komaromy et al., 2000).

Unfortunately, research indicates that health care professionals in the personal care home setting may be less prepared to provide optimal care to dying residents and have access to fewer educational and consulting resources than their counterparts in acute care settings (Ersek et al., 2000). Forbes (2001) conducted a study to describe the end of life in one personal care home in the United States from the perspective of residents who are chronically ill and declining, their family caregivers, and staff.

Qualitative methods, including formal and informal interviews, participant observation and health record abstraction were used to describe the end of life for 13 nursing home residents. Forbes (2001) concluded that one of the reasons that residents were vulnerable to inadequate care at the end of life care was because of a lack of educational preparation for death and dying within and across disciplines. Ersek et al. (2000) also stated that although deficiencies in health providers' knowledge of end of life care have been found across many health care settings, there is some evidence that the educational needs of nurses in personal care homes are greater than those in other settings because nurses in this setting were less likely to have had continuing education courses about palliative care. According to Ross et al. (2000), those concerned with ensuring an optimal quality of life for seniors dying or living with a life-threatening illness are provided with little direction regarding their practice. In the literature, nurses identified that the specific needs of dying nursing home residents included pain relief, the maintenance of dignity and being accompanied in the final stages of death (Komaromy et al., 2000), with the majority of the nurses expressing the need for further education in areas related to palliative care and pain management (Gibbs, 1995). Wilson (2001) stated that knowledge of pain management is as important in personal care home settings as it is in other settings. However, personal care home nurses' lack of knowledge about pain management was a common finding identified in studies by other researchers as well (Ersek et al., 2000; Parker & De Bellis, 1999). Gibbs (1995) attributed this lack of knowledge to the fact that nurses in this setting were less likely to have had continuing education courses about pain management and palliative care than nurses in acute care settings. In addition, Katz et al. (1999) reported that in addition to staff displaying minimal knowledge of the principles of pain control, many were not familiar with basic pain-relieving measures such as the use of special mattresses and analgesia. This finding is consistent with reports by Wilson & Daley (1998) who found that in addition to needing education regarding pain management, staff required further education in the area of comfort measures.

Ersek et al. (2000), in their study investigating the educational needs of nursing staff and certified nursing assistants in nursing homes regarding end of life care, also reported that participants in their research reported feelings of unease in administering medications, such as opioids, for fear of hastening death with analgesics. Major educational needs identified in this study also focused on such topic areas as advanced concepts of pain management in the nursing home setting: managing pain in cognitively impaired patients, understanding complex medication regimens and using "high-tech" interventions, such as epidural lines.

In the literature, several authors have stated that one approach to enhancing the care provided to dying personal care home residents is through staff education (Ersek et al., 2000; Froggatt, 2000; Gibbs, 1995). A study was conducted by Patterson, Molloy, Jubelius, Guyatt and Bedard (1997) with health care providers in three personal care homes to determine educational needs, barriers to meeting those needs, and to identify the preferred format for education. Of the 415 individuals asked to participate, 225 completed the questionnaire. The authors reported that need was expressed for the majority of the 35 educational topics in palliative care. The top three responses included: stress management for staff; information about the primary roles of the palliative care team; information about managing emotional impact on families. It should be noted that the authors indicated that they were not sure if the stress management for staff was specifically in relation to the care of the dying resident, or to the nature of the work in personal care homes in general (Patterson et al., 1997). While this study highlights the need for ongoing continuing palliative care education, the modest response rate and the differences in the number of respondents between groups of health care providers suggests that interpretation of findings should be made with caution. Surprisingly, the authors reported that when registered nurses, licensed practical nurses and health care attendants were grouped separately, no differences in the education needs between the groups of health care providers was found. More concerning however, is that 23% of respondents in this study indicated that they were not involved in palliative care, with 36 % of those respondents citing the reason for this to be because they had no contact with patients requiring this service. It is unfortunate that authors of this study did not discuss this concerning finding in the research article.

According to Ersek et al. (2000), educating nursing staff has been shown to increase knowledge and skills and to improve patient outcomes. Therefore, there is a need for educational programs designed to increase the personal care home staff's knowledge and skills regarding care of dying residents and their families (Ersek et al., 2000). Ferrell, Grant, Ritchey, Ropchan and Rivera (1993) assert that an educational program for nursing staff should assist in correcting some of the misconceptions about the interventions for pain and provide information on assessment, pharmacology, and other aspects of pain management. These authors stated that such education is necessary to ensure professional accountability in this critical area of nursing practice.

According to Froggatt (2001), it is assumed that education is sufficient to bring about changes in practice. Matzo and Witt Sherman (2001) state however, that the acquisition of knowledge is only one aspect of education in palliative care nursing (Matzo and Witt Sherman, 2001). The failure to link education to nursing practice and subsequent clinical outcomes represents a major limitation in nursing knowledge (Degner et al., 1991). Furthermore, Cohen et al. (2002) stated that there is an emphasis on education in the literature that does not take into account the beliefs and emotions of nurses. Therefore, education must include self-care, self-healing, the resolution of issues of loss and grief, and mutual support (Matzo and Witt Sherman, 2001). It has also been identified that while educational courses have their place in developing new practices, they need to be undertaken in conjunction with other initiatives that ensure the organizational culture of the institutions involved is addressed (Froggatt, 2001).

Care Provider Attitudes/ Beliefs

The prevailing attitude of our society towards death continues to be "death-defying" (Egan & Labyak, 2001). According to Egan and Labyak (2001), acceptance of death as a natural process is difficult and offensive. It should be noted however, that different cultures perceive the act of dying and death in different ways. The concept of culture includes the common values, beliefs, traditions, norms, symbols, language, and social organization of a particular group (Kemp, 1999). According to

Kemp (1999), culture is affected by ethnicity, socialization, religion and other forces, including common experiences. That is why Kemp (1999) proposed that health care providers can be viewed as a distinct subculture. The way nurses perceive the act of dying – as painful, upsetting, as a blessing, or indifferently – influences the type of care that they give a dying resident during his or her last days in the personal care home (Mullins & Merriam, 1983).

There is evidence in the literature that nurses working in the personal care home setting are afraid of death. Komaromy et al. (2000), in a study that investigated the quality of care provided for those dying in residential and personal care homes in England, reported that while some staff said that they felt unable to cope with all the extra work demands which a death placed on night staff, other staff revealed that they did not like to work night shifts because they were afraid of death at night. The researchers did not elaborate on the nature of staff's fears about death at night versus during the daytime. Feelings of fear regarding death were also expressed by staff members in Forbes' (2001) study describing end of life care in a nursing home in the United States. While staff in this study also identified that they were afraid of death, the researchers did not present a discussion of the source of this fear.

Caring for dying persons in nursing care homes does not always appear to engender fear in staff, however. Cohen et al. (2002) investigated nurses' attitudes to palliative care in nursing homes by examining the cognitive, affective and behavioural information provided by study participants. A sample of 228 nurses working in nursing homes completed a questionnaire, using free response methodology. The results showed that participants had either a positive or negative attitude to palliative care. The researchers found that the attitudes towards palliative care of those nurses who were currently working in palliative care were significantly more positive than the attitudes of those who were not, but this disappeared when they ceased working in the area. The researchers postulated that there is an emphasis on education in the literature, which does not take into account the beliefs and emotions of nurses. (Cohen et al. (2002) stated that the nurses had strong attitudes (few were neutral) towards palliative care in nursing homes because they are working with dying patients daily, whether they are practicing palliative care or not.

Staffing Levels and Lack of Time Available for Dying Residents

The nursing care required of terminally ill residents exert considerable demands on staff time. Komaromy et al. (2000) stated that increased demands on the personal care home staff when a resident was dying include extra nursing care, spending as much time as possible with the resident, and supporting visiting family and friends. However, staff find it difficult to devote the time needed to attend to these facets of caregiving. This time crunch may be a function of the staffing patterns of most nursing homes. Such patterns typically do not take into account labour intensive nature of care that needs to be provided to both patient and family at the end of life (Main, 2002; Parker and De Bellis, 1999; Wilson, 2001).

Kayser-Jones, Schell, Lyons, Kris, Chan and Beard (2003) conducted a study to investigate the physical environment and organizational factors that influenced the process of providing care to terminally ill nursing home residents. The design and methods used to obtain data were participant observation, interviews, and event analysis in two facilities (Kayser-Jones et al., 2003). While it should be noted that the authors acknowledged that the findings from their study are not generalizable because the research was conducted in only two nursing homes, inadequate staffing and a lack of supervision were identified as critical factors in the care of residents in nursing homes - information consistent with other reports in the literature. These authors (Kayser-Jones et al., 2003) reported specifically however, that inadequate staffing in personal care homes caused physical, psychological and emotional pain to residents and their families and inadequate care for dying residents. Moreover, staff felt overwhelmed, overworked and frustrated knowing that they could not provide a high standard of care (Kayer-Jones et al., 2003). The lack of time and staff available to care for dying residents would thus appear to have far reaching ramifications for all concerned.

A similar study examining the profile of 45 residents who were identified by nursing home staff as dying in 10 South Australian nursing homes, found that nurses experienced guilt and stress in looking after residents who were dying, particularly because of nurses' inability to sit and just "be with" the dying resident when he/ she had no family, and reported that nursing staff consistently identified a lack of time to provide the quality of care they wanted to give to residents and their families (Parker & De Bellis, 1999). These findings are consistent with Ersek et al. (2000) who indicated that lack of time and expertise to provide quality care to dying residents was often cited as a major source of stress for nurses and certified nursing assistants in personal care homes.

There is evidence in the literature that time constraint and staffing leave challenges faced by personal care home staff are recognized by the administration in personal care home settings. Komaromy et al. (2000) reported that 21% of nursing home heads recognized that inadequate staffing levels adversely affected the quality of care that staff were able to give to dying residents. In this study (Komaromy et al., 2000) 60% of the nursing home heads saw terminal care as a priority and said that if there were not enough members of staff on duty to allocate someone to sit with residents who were dying, then some routine tasks would be left undone. The researchers indicated however that these statements were not entirely supported by the heads of homes' actions or the observations of terminal care made during the study. For example, the researchers reported that certain routines like meals were strictly adhered to, even if a death had occurred shortly before a mealtime (Komaromy et al., 2000).

Avis et al. (1999) suggested that nursing home administrators acknowledge that there are difficulties in maintaining appropriate expertise in their care settings because of the high turnover of care staff and their lack of experience (Avis et al., 1999). Zimmerman, Sloan, Hanson, Mitchell and Shy (2003) stated that understaffing coupled with high staff turnover isolates dying residents in personal care homes and disrupts the consistency and continuity of care. In the literature, one factor identified as contributing to staff turnover is the fact that staff who work in settings where incapacitated individuals live out their final days and weeks of life face the problem of finding rewards from daily activity which lacks the stimulus and challenge of recovery care (Benoliel, 1973). Benoliel (1973) noted that nurses who work in personal care homes have acknowledged that one of their major problems lies with feeling that they have essentially been left with the challenge of taking care of people who are living out their time abandoned by their families and society in general. Teno (2002) asserted that addressing staff turnover is an important public policy concern and stated that future palliative care interventions will need to take into account "this persistent reality of nursing homes" (p.295).

Lack of Physician Support

Another barrier to the provision of palliative care in the personal care home setting is the lack of a physician's presence in this care environment. In the literature, authors report that contact with physicians is limited in nursing homes (Gibbs, 1995; Wilson & Daley, 1998). Whereas hospitals must always have physicians present, personal care homes may be required only to have physician services available as needed (Wilson, 2001). According to Hanson et al. (2002), physicians are rarely on site yet they remain responsible for medical treatment orders. This raises additional concern when a resident is new to the personal care home and may have to wait several days to weeks to be assessed by a physician. This reality is compounded by the fact that it also takes time for the physician and facility team to gather and assimilate all of the relevant information about a new resident and delineate his or her expressed wishes for end of life care (Travis, Bernard, Dixon, McAuley, Loving & McClanahan, 2002).

To date, there has been very little documented on the attitudes of physicians to caring for residents dying in personal care home settings (Katz, 2003). The minimal literature that does exist on this topic suggests that physicians acknowledge their unwillingness to spend more time in personal care homes and their need to rely on nurses' skills (Hanson et al., 2002). While the authors did not elaborate on the reasons for it, they suggested that physicians' unwillingness to spend more time in the personal care home may be due to both lack of remuneration and lack of knowledge regarding end of life care. Hanson and colleagues (2002) concluded that physicians could be given incentives to provide the time that advance care plan decisions require and education to recognize signs of limited life expectancy in this population. With residents entering personal care homes in more acute medical states, including some being admitted in the advanced stages of terminal disease, lack of a ready physician's presence may result in dying residents' needs not being identified or addressed in a timely way, thus significantly affecting the quality of the end of life care that they will receive. Wilson (2001) suggests that limited physician contact in the personal care home setting has been identified as posing a specific barrier to pain management in this environment (Wilson, 2001). Froggatt (2000) reported however, that even when the physician was available to nursing staff, a lack of support and willingness on the part of the physician to ensure that pain control was achieved, left nursing staff feeling isolated in their attempts to meet patient need in this area.

Lack of Privacy for Residents and Families

There are some environmental barriers within the personal care home setting that adversely affect the provision of care and support to dying residents and families. In a study previously discussed, Kayser-Jones et al. (2003) investigated the physical environment and organizational factors that influenced the process of providing care to terminally ill nursing home residents. The researchers used participant observation, interviews, and event analysis to obtain data in two nursing homes and asserted that privacy and space are necessary so that residents can have time with their families and bring closure to their lives (Kayser-Jones et al., 2003). The authors reported they found that residents were accommodated in small, crowded, multi-bed rooms, with little privacy. While this study only involved two nursing homes, published literature regarding the delivery of end of life care in this setting has consistently documented that the majority of personal care homes do not have enough space to provide privacy for dying residents and families (Wilson, 2001; Wilson & Daley, 1998). This reality has prompted some to liken the act of dying in a nursing care home to a "public spectacle" (Wilson, 2001, p. 536).

While privacy would appear to be valued by many in providing end of life care, there is research suggesting that it may negatively impact on care. In Avis et al.'s (1999) evaluation of a pilot community care project to extend hospice standards of palliative care to personal care home residents in Nottingham, privacy was equated with isolating residents who were dying from other people in the nursing homes, and therefore seen negatively by care providers because of such isolation made it difficult to meet residents' social and spiritual needs.

Families' Expectations

Death is always a family, as opposed to an individual, event (Reynolds et al., 2002), and the role of the family in personal care home settings is significant. Thus, the nature of family member expectations figure as a prominent factor influencing the care provided to dying residents. Family expectations of the nature and scope of care that nursing homes will deliver may present challenges for staff in the provision of palliative care - particularly when such care demands are perceived to be "unrealistic" (Wilson & Daley, 1998). According to Wilson (2001) families expect the same type of care to be provided in the nursing home that was provided in the home by themselves. As an example, Wilson (2001) indicated that families may believe a physician will visit every day instead of once a month. Factors fuelling such unrealistic expectations may arise because of the negative portrayal of nursing homes in the media. Wilson (2001) stated that the media reinforces negative images of personal care homes in that cases of abuse and poor management receive more attention in the media than positive images of this setting.

Unrealistic requests may also come from family members out of fear of withholding potentially helpful interventions. Travis et al. (2002) stated that family members often either will not or cannot choose to forgo aggressive curative care, such as hospitalization or tube feedings for an older relative, because they want to limit the likelihood that they may later feel regret that they withheld potentially effective treatment. Although it appears that this issue could be avoided through effective communication with families about disease outcomes and death, it has been reported that nurses do not feel appropriately prepared to engage in such discussions (Wilson and Daley, 1998). Wilson and Daley (1998) stated that although families may have delegated the physical care of the resident to the long-term care facility, they have not delegated their role as a family member. As such, personal care homes need to incorporate the family in the decision-making processes about care provided to dying residents. Hanson et al. (2002) reported that staff are aware of this need and that nurses and certified nursing assistants both reported that they attempt to offer family a role in care.

Hospitalization of Dying Residents

While it has been reported that between 67% and 90% (Hanson, 2003; MCHP, 2004; Reynolds et al., 2002) of residents will remain in the personal care setting to die, many nearing the end of life are transferred to hospital. Katz et al. (1999) reported that, of the 2180 deaths reported by the residential, nursing and dual-registered homes in England, 476 (22%) residents were transferred out of the home and died in hospital. In Manitoba, 36.8% of personal care home and chronic care residents who died were transferred to hospital at least once in the last six months of life (MCHP, 2004).

The necessity of such transfers has been questioned in the literature. An anthropological study conducted by Kayser-Jones, Weiner and Barbaccia (1989) described and analyzed the clinical and social-structural factors contributing to the hospitalization of personal care home residents. The researchers reported a portion of the findings of a larger study that investigated the social-cultural factors and other circumstances influencing the decision-making process in the evaluation and treatment of acute illnesses in nursing homes. The study used participant observation, in-depth interviews with physicians, nursing staff, personal care home residents and family members (100 in each category) and event analysis to gather data. The researchers claimed that 48.2% of resident transfers from personal care home to hospital were due to social-structural (i.e., lack of support services, nursing/ medical issues such as an insufficient number of adequately trained nursing staff and poor nurse-physician communication, and family pressure for transfer) rather than for clinical reasons, and thus could have been avoided.

Several other reasons for transfer of residents nearing the end of life from personal care home to hospital have been identified in the literature. Available personnel resources in personal care homes had important implications for transfer, specifically the number and type of nursing personnel available to care for dying residents (Bottrell, O'Sullivan, Robbins, Mitty, and Mezey, 2001). Travis et al. (2002) conducted an exploratory study that used a set of four obstacles (derived from both the existing literature and their own earlier work) that looked at hospitalization patterns and palliative care in the last year of life among residents in long-term care, to describe the diverse end of life scenarios observed for a group of residents in a long-term care facility. The researchers obtained data from a retrospective chart review and both quantitative and qualitative methods of data collection and analysis were used to examine the end of life experiences of all nursing home residents who died on the nursing care unit of a large continuing care retirement community during an 18-month period. The researchers stated that it may take a hospital admission for the care home staff, resident, and family members to understand, recognize, and agree that the resident is truly in the terminal phase of life. In addition, hospitalization may be the clinician's only option in response to a resident's terminal decline, if advance care planning was not or could not be addressed with the resident or family prior to the need for hospital care (Travis et al., 2002). Furthermore, Bottrell et al. (2001)

indicated that although many clinicians support the idea of retaining the dying resident in the home, others are concerned that, given the uneven history of quality of care in personal care homes, failure to transfer residents to hospitals may restrict access to necessary care and result in unnecessary suffering and hastened death.

Mezey, Dubler, Mitty and Brody (2002) stated that transfers of dying residents to hospital should be dictated by the needs and desires of the resident, not by the resources of the setting. Kovach et al. (1996) stated that this particular group generally fairs poorly when admitted to acute care facilities and therefore there is a need to study ways in which personal care homes can possibly reduce the need for acute care admissions. Generally in Canada, the trend is not to transfer dying residents from personal care home to hospital. Fisher et al. (2000) reported that more and more residents are remaining in the personal care home for end of life care. This suggests however, that the complexity of care provided in this setting is subsequently increasing (Patterson et al., 1997).

In conclusion, there is much documented in the published literature in support of the provision of end of life care to residents in personal care homes. However, there is equal if not more attention outlining the inherent challenges in the provision of such care in this setting. The assumption that palliative care, as derived from a cancer care model, is appropriate for personal care home residents can be questioned in two ways. First, the transition from life to death, in personal care homes, is less distinct and differs from the clearer demarcation between life and death that occurs for patients who die in hospices (Froggatt et al., 2000). Secondly, there is little work that has explored the wishes of older people themselves, regarding the manner of their end of life (Froggatt, 2001). Also, little is known about how long-term care facilities deal with issues of death and dying (Wilson & Daley, 1998). Further work is needed to articulate the transition from life to death in personal care homes in order that appropriate end of life care can be offered to residents (Froggatt, 2001). There is little research exploring the needs of dying older people either within the wider population or more specifically within personal care homes (Froggatt et al., 2000). In addition to this, quality indicators for the provision of effective care in this setting (e.g. functional status, activity involvement, eating, nutrition) may have little relevance to effective end of life care (Forbes, 2001). According to Smith (1998), it is important to recognize that personal care homes have developed their own philosophy of care to respond to particular needs of client groups, mostly older people. Personal care homes are homes for life which may offer a different philosophy and care culture to that in specialist palliative care services, which care for people who are dying (Smith, 1998). Although death in nursing homes is common, nursing home care emphasizes rehabilitation rather than excellence in end of life care (Reynolds et al., 2002). Traditionally, the emphasis of regulatory policies has been on restorative care (Ersek & Wilson, 2003). According to Engle (1998), a shift of emphasis is needed to address comfort care rather than focus on maximizing function. Now is the time for research and demonstration programs to help nursing home residents, families and health care providers to provide competent, coordinated and compassionate end of life care (Teno, 2003). Wilson (2001) believes that research by nurses is needed to improve end of life care in nursing homes.

The Nurse and the Provision of End of Life Care

Nursing's history reveals the compassionate care of the dying and acknowledges that human caring exists beyond cure (Matzo & Witt Sherman, 2001). Nurses have a pivotal role in maximizing end of life care (Valente, 2001) and they are often the primary care providers (Hall et al., 2002). As patients shift from a sick to a dying role, it is the nurse who assumes the dominant care provider role (Vachon, 2001). According to Matzo and Witt Sherman (2001) the value of the nurse's role in ensuring the quality of life and dying is acknowledged and respected by all health disciplines. Furthermore, terminally ill patients often approach nurses first and ask for their assistance to discuss end of life options before they ask other professionals (Valente, 2001). Both families and patients depend on nursing staff to provide knowledge about appropriate treatment options and to provide support and guidance in decision-making (Wurzbach, 2002). This is because nurses play an important role in preparing families for death situations and developing interventions to meet the needs of these patients and their families (Goetschius, 1997). In the personal care home setting, registered nurses in particular make significant contributions to enhance terminal residents' quality of life (Wilson, 2001). For example, Bottrell et al. (2001) acknowledged that nurses play a substantial role in personal care home-to-hospital transfer decision-making. Regardless of setting, it has been stated that the end of life is not just one more stage of life; as the final stage, the nurse is entrusted with an incredible obligation and responsibility (Matzo, 1997).

A review of the literature about the role of the nurse in the provision of end of life care led to the identification of three categories of care provided to dying patients by the nurse. The categories included: the supportive role, the doing-for role, and the assessment role.

The Supportive Role

Providing support for others is considered to be a key aspect of nursing (Oberle & Davies, 1992). Krishnasamy (1996) conducted an exploratory, descriptive study to identify the nursing behaviour patterns perceived as being helpful and unhelpful by by hospitalized cancer patients (n = 8). The purposively selected sample of four male and four female participants were asked to describe the most helpful and least helpful things done for them by nursing staff since admission or at any time during their contact with them. Participants were then asked to explain why each item was either helpful or unhelpful. It was found that patients' and families' perceptions of helpful nursing behaviours are those that demonstrate emotional support, including information that one is cared for, loved, or esteemed (Krishnasamy, 1996).

Support was discussed in the context of listening to both patients and families (Larson, 1984; Chekryn-Reimer & Davies, 1991; Ouimet Perrin, 1997; Wilson, 2001), and providing an environment whereby concerns and feelings can be explored (Chekryn-Reimer & Davies, 1991; Wilson & Daley, 1999; Hall et al., 2002). Chekryn-Reimer & Davies (1991) stated that in doing this, nurses create an environment of caring and working together and establish a sustaining presence and a sense of security despite the uncertainty. This sense of security in the environment was also created with the nurse being present for the family and patient (Goetschius, 1997). Gauthier (1998) stated that loneliness, particularly for patients, is a main concern and that in these circumstances providing accompaniment becomes of prime importance in the professional's work.

Nursing support was also presented in terms of communication. Wilson (2001) stated that it is important that nurses be able to communicate openly, explain changes in condition, and answer questions honestly. Wurzbach (2002) reported on a project that was implemented to determine what policies nursing homes in Wisconsin follow related to resident decision-making about end of life treatment. The researcher developed a survey that was mailed to 370 nursing homes. While a 50% response rate was achieved, there was no way to determine who actually responded and who did not. Therefore, it is unclear whether it is the residents' perspectives captured in this study or those of nursing home administration. She stated that ongoing conversations not only provide information but also essential social support for older adults and families (Wurzbach, 2002). One author discussed communication and the supportive role of the nurse in terms of the importance for nurses to assist clients with the expression and achievement of their rationally chosen desires (Ouimet Perrin, 1997).

Despite the agreement that nurses should and do provide supportive care to the terminally ill, there is little description of what supportive care is or of how nurses provide such care (Davies & Oberle, 1990). Oberle and Davies (1992) stated that most research has focused on the nurse's role of "doing-for", and thus has failed to recognize the interaction between the nurse as professional and the nurse as person (Oberle & Davies, 1990). To redress this gap in knowledge, Oberle and Davies conducted an in-depth examination of one nurse's practice in a palliative care role. The expert supportive care nurse described in-depth her care for 10 palliative care patients. The data from this study resulted in the generation of the Model of Supportive Care for Nursing: a model, comprised of six interwoven but discrete dimensions: valuing, caring, empowering, doing for, finding meaning and preserving one's own integrity (Oberle & Davies, 1990). The authors defended the unorthodox methodological approach used in this study by stating that an inductive method is particularly appropriate when the knowledge base is sparse and when one wants to gain a fuller understanding of what constitutes reality for the informants in a particular situation. The applicability and relevance of this model to other areas of nursing practice is an area requiring further investigation.

The Assessment Role

Nursing assessment involves assessment of both the patient and family. Regarding the patient, nursing responsibilities include physical and psychosocial assessments (Rose, 1995), as well as appraising the effectiveness of the treatments implemented for the management of end of life symptoms (Ersek et al., 2000; Wilson, 2001). In addition to the assessing these aspects of patient care, Gillick, Berkman and Cullen (1999) stated that it is essential to discuss future end of life care preferences with patients and families so that preferences can be met. Ouimet Perrin (1997), in a report exploring the nurses' potential to impact end of life care, identified that the nurse assumes an important role in determining patients' decision-making capacities and abilities to communicate decisions.

Regarding the assessment role of the nurse concerning the family and end of life care, the literature suggests that nurses should assess family for their knowledge and abilities to provide care to their loved one, develop interventions to help them cope with their feelings and identify how they want to be involved in the end-of-life process (Goetschius, 1997). In addition to this, Goetschius (1997) stated that nurses should assess what families know about the death process. End of life nursing care does not end with the patient's death. According to Lethem (1999), nurses must continue to assess bereaved family and recognize the warning signs of an adverse grief reaction to determine whether referral an appropriate bereavement support service is required. In this way, nurses can relieve at least some of the suffering (Lethem, 1999).

The Doing-for Role

Mcilfatrick and Curran (2000) attempted to provide the distinction between the "doing" of end of life nursing and "being" a real presence for the dying patient and their family. They reported the findings of a study to examine district nurses' perceptions of palliative care services within the community setting. A questionnaire which focused on the key areas of defining palliative care, perception of roles, communication, service provision and the educational and training needs of district nurses was completed by nurses (n = 66) in two communities in Northern Ireland. The researchers stated that aspects of care associated with symptom management and maintaining quality of life may be better understood within the traditional context of doing, while the other aspects of care, such as promoting independence and providing psychological care and support can be considered as being with the patient. These authors also suggested that the doing-for aspect of the nurse's role not be underestimated or undervalued, because in the provision of such care the nurse is also providing emotional support and care for both the patient and family.

In a qualitative study used to identify a list of critical nursing behaviours in care for the dying, Degner et al. (1991) asked 10 experienced palliative care nurses and 10 nurse educators to describe situations in which a student or graduate nurse had displayed very positive or very negative attitudes to care for the dying. Degner et al. (1991) stated that the critical nursing behaviours identified in their study could serve as a beginning guide for structuring nursing education programs about care for the dying. The researchers emphasized that their framework of nursing behaviours focused on intervention rather than the assessment phase of practice, thereby clearly defining the nurse's role which helps to challenge the assumption that there is "nothing left to do" for the dying and their families. Behaviours identified by Degner et al. (1991) included: responding during death scene, providing comfort, responding to anger, enhancing personal growth, responding to colleagues, enhancing quality of life during dying and responding to the family.

Other authors have identified specific tasks or responsibilities that make up the doing-for role of the nurses in the provision of care to dying patients. Some have emphasized the importance of the nurse's role in the treatment of end of life symptoms (Ersek et al., 2000; Valente, 2001), such as ensuring that appropriate medication and dosages be prescribed and that they are properly administered (Gauthier, 1998; Hall et al., 2002). Others highlighted the nursing role in terms of patient/ family advocate, while also acting as the communication link between the patient and family and personal care home staff. According to Hall et al. (2002)

nurses were primarily responsible for documenting end-of-life issues and communicating with other team members. It was also stated that nurses should facilitate discussion of end of life care between physicians and competent elders (Ouimet Perrin, 1997), and that the nurse is responsible for communicating any changes in a patient's condition to the physician (Wilson, 2001). In regard to the patient and family, Lethem (1999) stated that the nurse is responsible for ensuring that information passed to them from other professionals is understood and assimilated, trying wherever possible to realise the resident's wishes regarding his or her care. According to Valente (2001), nurses have a key role in evaluating a person's end of life wishes and improving communication and education about those options. Nurses were identified as being responsible for initiating discussions with families about changes in the patient's condition (Hall et al., 2002; Lethem, 1999), and for giving as much information as is realistically possible about what will happen when their loved one dies (Goetschius, 1997). In a study by Wilson and Daley (1999) family members identified that participation in the dying process was important. Participation included being involved in decision-making, understanding the dying process, and being present at the time of death (Wilson & Daley, 1999). Therefore, nurses should ensure that families are included in the care of dying patients, and their need for privacy should be respected (Wilson, 2001). Wilson (2001) also stated that families identified the importance of demonstrating concern for the family. Concern for family was illustrated for example, when staff took the time to come to a patient's room to inquire about how the family was doing.

Although the vast majority of the published literature investigating the role of the nurse in the provision of end of life care studied nurses who provide palliative care in clinical areas other than personal care homes, one might conclude that the findings from these other studies are applicable in the personal care home and are therefore transferable to this setting. According to White, Davies and Smeal (1997), the role of the palliative care nurse, the underlying philosophy of the position, expectation of service delivery and standards of care and responsibilities remain the same regardless of location. However, the unique characteristics of and factors influencing the personal care home environment may mean that the findings from previous work examining care of dying individuals may not be completely applicable or generalizable.

In an attempt to redress the dearth of empirical information examining nursing behaviours deemed to be critical in care of the dying patient, Degner and colleagues have conducted a series of qualitative studies that have generated an inductively derived list of "expert" nursing behaviours as they relate to the care of the dying in adult palliative care (Degner et al, 1993), adult intensive care (McClement & Degner, 1995), adult medical units (Harbeck, 1995), pediatric care (Hawkins, 1995), and the community/ home care (Helwar, 1994). The nature of such care has not been examined in a personal care home setting, however. Thus, the list of nurse behaviours generated to date (Table 1) may be incomplete.

There is a lack of literature describing the nature of the work of registered nurses in personal care homes. Leppa (2004) attempted to describe the nature of nursing work in long-term care nursing home environments by conducting a study to explore the nature of this work and comparing it to the nature of nursing work in the intensive care unit environment. The researcher used focus groups consisting of five to seven key informants (registered nurses and licensed practical nurses, n = 113) from 35 nursing units in nine facilities. The researcher reported that participants emphasized the complexity of the medical and psychosocial needs of their patients as one theme in the nature of their nursing work. Nurses also identified the psychosocial needs of the patients' family members and how dealing with these needs is an unrecognized and often extremely time consuming aspect of long-term care nursing work. The need to work with and through nursing assistants was another common theme identified in the uncertainty of nursing work in long-term care. The authors reported that participants reported needing "eyes in the back of their heads" (p.29) to supervise three to five nursing assistants who, in turn, were providing care to the 10 to 30 residents in an average nursing workload. Leppa (2004) concluded that the long-term care nursing work environment is a complex, demanding and interesting one that is different from, not less than, nursing work in intensive care units. This researcher's work is admirable in that it challenges the assumptions that nursing in long-term care nursing homes is less intellectually challenging, less physically demanding, and less skilled work than nursing in acute care environments (Leppa, 2004). However, the researcher compared her findings, based on the responses from registered nurses and licensed practical nurses, to data about intensive care unit nursing that came from a study 15 years prior and involved registered nurses only. Leppa (2004) indicated that "one of the most interesting areas of nursing work uncertainty in long-term care environments" (p. 31) is the range of goals of patient care – in particular, how and when to change the goal of care to supporting patients at the end of life. The researcher stated that nursing leaders will need long-term care nurses to develop and evaluate health care policy regarding end of life care as the population ages and the need for nursing home beds increase. It was not explained however, how nurses will assist to accomplish this, especially when she too has acknowledged the findings of others in the literature that the shortage of qualified nursing staff in a work environment already places a significant burden on nurses with respect to the current workload of nurses on personal care homes. For example, Kayser-Jones et al. (1989) studied factors contributing to the hospitalization of nursing home residents and discussed the burdens on nurses of having to provide care to a number of heavy care patients in addition to supervising the care provided to a large number of other residents. The authors described this as "an impossible task!" (p. 507) and related the shortage of nursing staff in this setting to the resulting tendency to transfer dying residents to the hospital unnecessarily when the resident's condition deteriorated.

A review of the literature revealed support for personal care homes as appropriate settings for the provision of palliative care. Authors have also commented, however, about some of the challenges inherent in delivering such care in this setting. Despite these challenges, what is consistently documented is the nurse's pivotal role in the personal care home with respect to the delivery of palliative care. Identification of nurse behaviours deemed critical to the care of dying residents in personal care homes would serve to enhance the palliative care that nurses deliver and may assist care providers in overcoming some of the challenges to providing quality palliative care in the personal care home environment.

Summary

This chapter has reviewed five categories of literature that are relevant to the proposed study including: i) a definition and explanation about the philosophy of palliative care; ii) a presentation of recent developments to the concept of palliative care iii) an overview of the personal care home setting as an appropriate setting for the provision of palliative care; iv) the challenges to providing palliative care in this care setting; and v) the identification of the role of the nurse in the provision of end of life care. The next chapter will provide a description of the theoretical perspectives selected to guide the project.

CHAPTER THREE

THEORETICAL FRAMEWORK/ CONCEPTUAL MODEL

Introduction

Theoretical frameworks and conceptual models can be used to provide sensitization about, and a context for, research in a specific field of interest. A "theory" is a notion that explains experience, interprets observation, describes relationships, and projects outcomes (Parker, 2001). Conceptual models are sets of general concepts and propositions that offer guidance to endeavours but no distinct direction (Parker, 2001). According to Parker (2001), nursing theories and conceptual models are patterns that guide the thinking about, being and doing of nursing and therefore provide structure and substance to ground the practice of nursing. Therefore, it can be said that nursing theories serve to guide nursing research conducted in a particular clinical area. This chapter will provide a description and critique of the frameworks used to guide this study. The relevance and appropriateness of the selected frameworks will be described. Where appropriate, revisions to the frameworks, based on the current literature examining care of the dying in the personal care home setting, will be proposed.

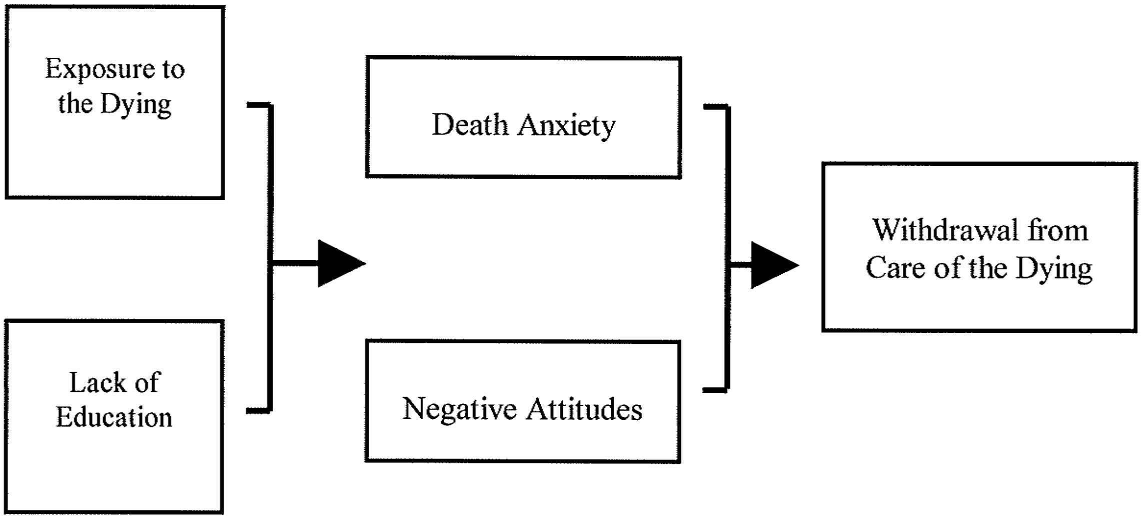
Two conceptual frameworks were used to guide this study. The first was derived from the theoretical perspective advanced by Quint (1967) in her Model of Nursing Care of the Dying. The second was drawn from Benner's (2001) work detailing nursing practice in her "Novice to Expert" Model.

Quint's Model of Nursing Care of the Dying: Framework Description and Critique

Jeanne Quint is a pioneer in the field of nursing research and thanatology whose work has transformed the care of patients, especially at the end of life. As a nurse, researcher, and teacher, Quint brought a special perspective to her work, focusing on patients and their families, and on the nurses who care for them. She acknowledged that professional nurses often hold positions in which they could assure considerable well-being of dying patients and their families (Quint, 1967). However, she maintained that nurses have not been prepared for this kind of responsibility in their educational programs (Quint, 1967). Quint's research into how nurses are educated regarding the provision of end of life care identified several findings of importance. First, she identified that the majority of students entering nurse's training were likely to have had minimal exposure to death and dying. Second, she (1967) postulated that when students are assigned to care for dying patients without the requisite educational ability and emotional support from others to do so, inadequate nursing performance results. Third, it was Quint's assertion that the culmination of these factors makes the student susceptible to the impact of unanticipated and emotionally unsettling death-related events, and that traumatic experiences can produce a nurse who carries a deep sense of personal inadequacy. Finally, Quint (1967) theorized that lack of positive experience in care of the dying would decrease the likelihood of a nurse's personal involvement with the death of a patient.

Quint's (1967) findings led to recommendations for significant changes in the way that nurses are prepared in their educational programs to care for dying patients. She concluded that if the care of dying patients is to have a more rational and systematic base, then education of those in the health profession with respect to this care is of critical importance. Otherwise, nurses exposed to care of the dying without accompanying educational support would adopt the behaviour of other professionals around them and limit their involvement in death-related situations (Quint, 1967).

Figure 1. Quint's Theoretical Model:



Critique of Quint's Model:

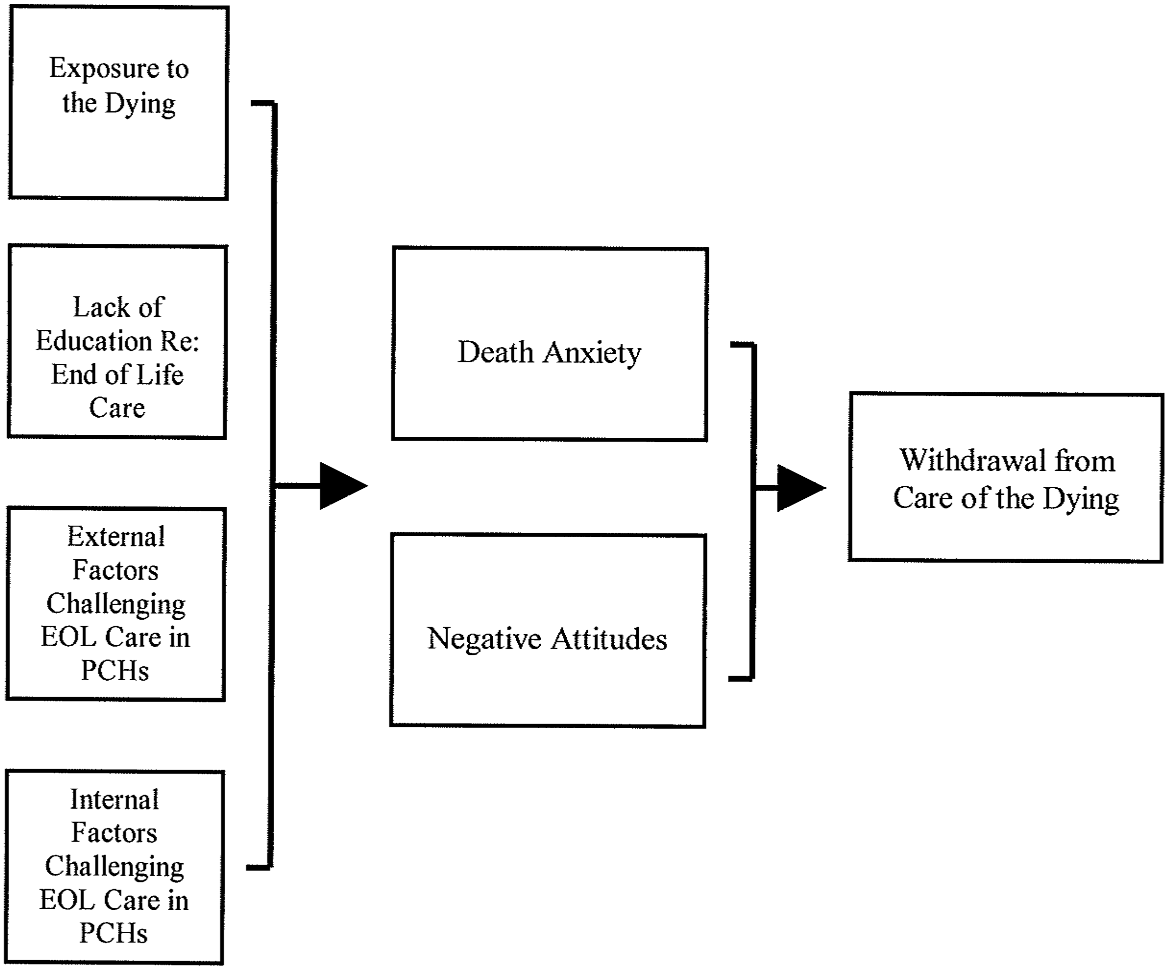
Degner et al. (1991) acknowledged that although the theoretical orientation suggested by Quint's (1967) work has been inductively derived, it has not been tested empirically. However, some empirical studies have provided support for her perspective. Interviews with practicing nurses (n=68) suggested that less experienced nursing personnel demonstrated a relatively more open attitude toward death in comparison to those nurses with greater experience (Pearlman, Stotsky, and Dominick, 1969). Those nurses with more experience tended to feel uncomfortable or to avoid talking about death with a dying patient. In contrast, less experienced nurses indicated that they felt they could handle the care of and communication with dying patients easily and directly. Similarly, a survey of hospital nurses (n=188) conducted by Shusterman and Sechrest (1973) found that more experienced nurses tended to be more satisfied with traditional ways of caring for dying patients, such as not informing them of their terminal prognosis, and isolating them from other patients.

Regarding the notion of death anxiety, Mullins and Merriam (1983) postulated that increased anxiety about death stimulates nurses to spend more time contemplating their own demise and may also stimulate greater empathy with those around them who are facing their own death. Mullins and Merriam (1983) conducted a study to determine the effectiveness of a set of workshops attended by nursing home nurses from four facilities to promote cognitive gains and stimulate increased positive attitudes toward the elderly and the dying. The effectiveness of the treatment in promoting increased knowledge about the dying patient and the elderly, in fostering positive attitudes toward the elderly, and in facilitating less anxiety about death was assessed by comparing pre- and post-test data from the experimental and control groups obtained through the use of four measurement instruments. Random assignment of nursing personnel to separate experimental and control conditions within one nursing home was not feasible. Therefore, the researchers randomly assigned the four nursing homes to treatment and control groups, and attempted to limit the effect of inherent differences between the facilities themselves as a factor in the findings of the study by controlling for nurses' experience exercised through statistical procedures. The Solomon four-group design was used to control the pre-test/ post-test interaction. Mullins and Merriam (1983) reported that their finding that death anxiety was greater among those nurses who received the education is not an indication that the workshops were ineffective. The researchers suggested that in realizing that their own anxiety has been heightened by simply hearing about death and dying, nurses may also more fully understand the feelings of those persons to whom they are administering and that this anxiety will hopefully be transformed into a constructive energy outlet stimulating greater patient understanding. The suggestion from Mullins and Merriam (1983) that death anxiety will stimulate the nurse to provide better care to dying patients is thought-provoking and may be true to some extent. However, Arnold and Egan (2004) note that nurses should be aware of their own feelings, responses and reactions to death so they can convey caring, acceptance and respect for patients and their families and communicate effectively. Otherwise, the combination of death anxiety and limited resources or support systems to enable the nurse to explore and express thoughts and emotions about dying and dying result in nurse behaviours such as emotional distancing, avoidance and withdrawal from the dying patient and their family (Arnold & Egan, 2004; Vachon, 2001). Quint's model has received support in the personal care home literature by Cohen et al. (2002) who investigated nurses' attitudes to palliative care in nursing homes by examining the cognitive, affective and behavioural information provided by study participants. The researchers found that the attitudes towards palliative care of those nurses who were currently working in palliative care were significantly more positive than the attitudes of those who were not, but this disappeared when they ceased working in the area. Cohen et al. (2002) stated that the nurses had strong attitudes (few were neutral) towards palliative care in nursing homes because they are working with dying patients daily, whether they are practicing palliative care or not. The authors explained that as the nurses are currently working with patients with a terminal illness, they may have stronger views on their care than people who have little or no contact with such patients. The authors stated that attitudes resulting from experience in palliative care are not very consistent and that attitudes only persist as long as exposure to palliative care continues. They postulated that while nurses are investing substantial physical and emotional energies in palliative care, they focus on the positive aspects of this approach to care in order to maintain their level of commitment. However, when they leave palliative care, there is no longer any need to maintain such a high level of commitment to palliative care (Cohen et al., 2002). Cohen et al. (2002) concluded that as far as education is concerned, their findings indicate that knowledge alone insufficient in fostering a positive attitude; education may need to address beliefs and emotions of nurses as well as experience.

Revision of Quint's Model Based on the Literature:

Quint's model provides a useful place from which to consider the factors influencing the provision of end of life care to residents dying in a personal care home setting. A review of the literature examining end of life care in a personal care homes (detailed in Chapter 2) revealed that additional factors not currently reflected in Quint's (1967) model affect the care provided to this patient population. These include external factors that originate outside of the personal care home environment, which are beyond this setting's control. External factors include such things as the current profile or description of what constitutes "typical" personal care home residents, terminal diagnoses in the residents, and symptoms and disease trajectories. Internal factors, those factors that originate within the personal care home environment and thus factors over which the care facility may have some control include: lack of knowledge regarding palliative care, care provider attitudes/ beliefs, staffing levels and lack of available time for dying residents, lack of physician support, lack of privacy for residents and families, families' expectations and hospitalization of dying residents. Quint's model has thus been revised in the current study to reflect these factors and is depicted in Figure 2.

Figure 2. Revised Theoretical Model:



<u>External Factors</u> = those challenges identified in the literature that originate outside of the personal care home environment and which are beyond the setting's control (e.g. current profile or description of what constitutes "typical" personal care home residents, terminal diagnoses in the residents, and symptoms and disease trajectories)

<u>Internal Factors</u> = those challenges that originate within the personal care home environment and which the setting may have some degree of influence over (e.g. lack of knowledge regarding palliative care, care provider attitudes/ beliefs, staffing levels and lack of available time for dying residents, lack of physician support, lack of privacy for residents and families, families' expectations and hospitalization of dying residents)

For a more detailed description of these two classifications of factors challenging the provision of end of life care in the personal care home setting, please refer to the Literature Review, Chapter Two.

Benner's (2001) Novice to Expert Model

The second theoretical perspective guiding this study concerns Benner's work examining the nature of expert nursing practice. Patricia Benner, a researcher, teacher and theorist, was interested in skill acquisition and clinical judgment in nursing practice, and articulating the knowledge and skill in practice in order to make it public, and visible. Benner (2001) adapted a model of skill acquisition that was originally developed by Dreyfus (1979) who studied the skill acquisition of chess players and airline pilots. Briefly, the Dreyfus model posits that, in the acquisition and development of a skill, one passes through five levels of proficiency: novice, advanced beginner, competent, proficient and expert (Benner, 1982). An important assumption of the Dreyfus model is that with experience and mastery, a skill is transformed which subsequently brings about improvement in the performance (Benner, 2001).

Benner (1982) postulated that the Dreyfus Model of Skill Acquisition could be generalized to nursing because it took into account increments in skilled performance based upon experience as well as education. Benner (1982) affirmed that it also provides a basis for clinical knowledge development and career progression in clinical nursing. Benner (1982) applied the original model's five levels of proficiency to nursing in an attempt to clarify the characteristics of nurse performance at different stages of skill acquisition (Figure 3).

Figure 3. Benner's Adaptation of the Dreyfus Model:

Level of Proficiency				
Level I: Novice	**Level II: Advanced Beginner**	**Level III: Competent**	**Level IV: Proficient**	**Level V: Expert**
Beginners have no experience with the situations in which they are expected to perform tasks. They are taught rules to guide action in respect to different attributes. Since novices have no experience with the situation they face, they must use these context-free rules to guide their task performance.	An advanced beginner has coped with enough real situations to note the recurrent meaningful situational components.	Competency develops when the nurse begins to see his/ her actions in terms of long-range goals or plans. This stage is characterized by a feeling of mastery and the ability to cope with and manage, but lacks the speed and flexibility seen in the next level.	The proficient nurse has the experience-based ability to recognize whole situations which enables him/ her to recognize when the expected normal picture does not present itself. Decision-making is now less laboured since the nurse has a perspective about which of the many attributes and aspects present are the important ones.	The expert has an intuitive grasp of a situation and zeros in on the accurate region of the problem without wasteful consideration of a large range of unfruitful possible problem solutions.

Benner (2001) stated that the study of proficient and expert performance should make it possible to describe expert nursing performance and the resultant patient outcomes. She also asserted that this knowledge can be used to further develop the scope of practice of nurses who wish to, and are capable of achieving excellence (Benner, 2001).

Critique of Benner's Model

Over the past decade, many authors have critiqued Benner's "From Novice to Expert" theory. Criticisms have been levied in four main areas: 1) the proposed stages of development, 2) use of the label "expert", 3) use of the concept of "intuition", and 4) the lack of a scientific foundation for the theory. These criticisms will be discussed in the following paragraphs.

Proposed Stages of Development

English (1993) stated that while Benner's stages to become an expert are clearly presented, the stages are merging points on a continuum that impede measurement. Nicol, Fox-Hiley, Bavin and Sheng (1996) agreed with English's assertion and suggested that a more detailed description of what those stages mean in terms of the component parts of nursing, especially the clinical and communication skills, was warranted. Shapiro (1998) also critiqued Benner's use of stages, characterizing the description of performance progression between the stages as theoretical and vague.

Use of the Label "Expert"

Rolfe (1997a) is critical of the seemingly mysterious way that expertise develops over time, and rejects that expertise is something largely outside the control of the nurse who is at a loss to account for it. Rolfe (1997b) also stated that when applied to nursing, this model of expertise is elitist and deliberately obscure. Critics have declared that if the expert nurse is to be a paragon of excellence and someone to be emulated, then an accurate description of expertise is required (English, 1993).

Furthermore, English (1993) stated that while Benner acknowledges that not all nurses will be able to become experts, no explanation is offered as to why all nurses who have worked for more than 5 years in one clinical area cannot become experts. Another author concurred with English's position that Benner's attempt to describe the expert in nursing is confusing. Cash (1995) stated that while on one hand Benner says that the label "expert" cannot be fixed on a person because it is the context which is important, Benner also states on the other hand, that the individual expert is characterized by a specific way of thinking. Rolfe (1997b) indicated however, that neither Benner nor Dreyfus and Dreyfus could explain precisely how the expert nurse makes decisions.

Use of the Concept of Intuition

English (1993) stated that while one feature of the expert is recourse to intuition, intuition as a concept is somewhat ambiguous. Moreover he asserts that Benner's failure to offere a proper description of intuition, and the ways in which nurses become intuitive constitutes a significant limitation to her work (English, 1993). Cash (1995) also took issue with the notion of intuition, but was more concerned that Benner's emphasis on the concept does not raise the status of nursing's knowledge claims, but rather fosters a nursing practice distorted by the unequal power relations with competing epistemologies such as medicine.

In 1996, Benner published a response to Cash's (1995) critique of her work. In that response she reinforced that the findings of her research do not suggest using intuition as a way to legitimize one's actions. Rather, she explained that the good clinician and scientist must seek to create an intelligent and respectful dialogue between intuition and validation. She stated that she does not suggest abandoning confirming and disconfirming reasoning. Benner (1996) also stated that expert performance always occurs in a context. One who performs excellently in most situations might be considered an expert.

Lack of a Scientific Foundation for the Theory

English (1993) stated that if it is to become a research-based profession, nursing practice should be founded on scientific knowledge. As such, clinical assessments must be based on explicit criteria and not the "hunches" of Benner's experts. English (1993) stated that insightful and attentive recognition of patient's needs derived from anything other than diligent observation, sound clinical knowledge and experience is denigrating to the majority of nurses. According to Paley (1996), English's critique of Benner's ideas comes from the perspective of cognitive psychology, while Darbyshire defends them against what he describes as a "positivist" attack. Darbyshire (1994) responded to English's (1993) critique and stated that Benner's work does not devalue science. Rather, Benner's work proposes that a viable alternative to traditional ways of understanding practice, theory and knowledge are possible (Darbyshire, 1994). Benner (1995) acknowledged that in some contexts, her work has been misunderstood as promoting "traditionalism" rather than articulating current understandings, knowledge, and skills from evolving traditions of nursing practice. She stated that in making distinctions between the natural sciences and the human sciences, she assumed that nursing practice must draw on both since nursing deals with the physiological, biological and medical sciences as well as the human sciences and even other healing traditions found in art and culture. Benner asserts that nowhere in her work does she argue for discounting science or scientific evidence.

While it is evident that Benner's theory has served as the source for much discussion and debate in the literature, it should be noted that literature abounds in support of the strength and utility of the theory she has generated. Shapiro (1998) noted that the model is very well defined and includes several levels that are easy to understand. English (1993) indicated that the strength of the model lies in the emphasis that is placed on clinical nursing care. There is also acknowledgement in the literature that that the model is adaptable in its design to fit any organization structure or setting (Shapiro, 1998; English, 1993). Furthermore, since the introduction of the model nearly 20 years ago, Benner's work has been the focus of many authors. In fact, Shapiro (1998) stated that Benner's model is the only developmental model that has endured the test of time. According to Shapiro (1998), it is for these reasons that the Benner model proves to be the best method for promoting nursing expertise and achieving positive outcomes.

Relevance and Appropriateness of Chosen Theoretical Perspectives

The frameworks discussed in this chapter were appropriate and relevant for use in this study. Taken together, these two theoretical perspectives provided a meaningful context from which to begin to examine and described expert nurse behaviours in caring for the dying resident in a personal care home.

Quint's (1967) perspective posited that nurses exposed to care of the dying without accompanying educational support would adopt the behaviour of other professionals around them and limit their involvement in death-related situations. The vast majority of practicing nurses have not received theoretical content related to palliative care in their basic nursing education programs. Thus, nurses working in a personal care home setting may feel that there is "nothing left to do" for terminally ill patients and their families, and minimize their contact with these individuals. This suggests that the knowledge level of the nurses regarding the principles and practices of palliative care is a significant internal factor within the personal care home setting influencing end of life care.

Benner's (2001) model has provided the means by which the knowledge embedded in the practice of "expert" personal care home nurses who care for dying residents and their families might be examined. Her work thus provides the rationale for the data collection methods to be used in the study, and ways in which nurse experts might be identified in the sample selection phase of the project.

Finally, past programmatic research examining expert nursing behaviours in care of the dying in various care settings (Degner et al., 1991; Harbeck, 1995; Hawkins 1995; Helwer, 1994; McClement & Degner, 1995) have also been grounded in these two theoretical perspectives. The generation of meaningful findings from these previous works attests to the relevance and utility of these frameworks for use in this study, and suggests that their use for this project is both warranted and appropriate.

Summary

This chapter has provided an overview and critical appraisal of the theoretical perspectives used to guide this study. The relevance and appropriateness of these perspectives as they relate to the proposed study has been described. Suggested revisions to these perspectives based on relevant literature have been presented. The next chapter will provide a description of the methods and procedures used to conduct the study.

CHAPTER FOUR

METHODOLOGY

Introduction

This chapter outlines the research methodology used to investigate critical nurse behaviours in the care of dying elderly residents in personal care homes. A description of the research design, study sample and setting, and approaches to data collection and data analysis procedures will be described. Issues of rigor as they apply to qualitative research are discussed. Ethical considerations regarding the execution of the study are identified.

Design

A descriptive-exploratory design was used to address the research questions posed in this qualitative study. The purposes of descriptive-exploratory designs are to: i) accurately portray the characteristics of persons, situations, or groups and/ or the frequency with which certain phenomena occur; and ii) to explore the dimensions of a phenomenon for the purpose of developing or refining a hypothesis about the relationships between phenomena (Polit & Hungler, 1999). Qualitative research designs are often used to examine phenomena about which little is known (Polit & Hungler, 1999; Streubert & Carpenter, 1999). Given the limited body of knowledge about what constitutes expert care of the dying in the personal care home setting, the use of a qualitative research design was deemed to be both warranted and appropriate to answer the proposed research questions as outlined in Chapter One.

Sample and Setting

***Sample*:** A purposive sample of ten registered nurses identified by their peers as being expert in the care of the dying elderly resident in a personal care home were recruited for participation in the study. (For a description of the process whereby nurse experts were identified, please see Appendix A). Purposeful sampling is a non-probability sampling method in which the researcher selects participants for the study on the basis of personal judgment about which individuals will be the most representative (Polit & Hungler, 1999). While it is recognized that registered nurses represent one facet of the interdisciplinary health care team that delivers palliative care, the focus of this study is specific to the practice and critical behaviours of the registered nurse in the provision of end of life care. This is in keeping with the previous research conducted investigating critical nurse behaviours in the care of the dying and enables the researcher to more readily compare and contrast the findings from this study with those generated in other care settings. Moreover, one of the theoretical perspectives guiding this study (Benner's model of expert nursing practice) was generated based on her work with registered nurses. Thus, the decision to focus on registered nurses in this study ensured that the sensitizing concepts in Benner's work were relevant and appropriate for the nursing population of interest for this study. The use of purposeful sampling is appropriate because the researcher's goal in this study was to obtain a sample of experts (Polit & Hungler, 1999). In qualitative research, a sample size of 10 is sufficient, given that the participants are able to provide insight and rich description related to the area under investigation (Munhall & Oiler, 1982). To ensure completeness of the nurse behaviours generated by participants, data collection continued until data saturation occurred. Polit and Hungler (1999) define saturation as the point at which data collection generates no new information, and the researcher finds repetition and confirmation of previously collected data (Streubert & Carpenter, 1999). Thus, while a sample size of ten participants was planned, the researcher was prepared to recruit additional participants depending on the completeness of the data and the extent to which categories and themes saturate.

Setting: In order to capture some of the contextual variation in the settings in which nurses care for dying residents samples of nurse experts were recruited from two distinctly different personal care homes in the city of Winnipeg. In order to ensure a large enough potential pool of nurse participants in the study from which to draw, each nursing home also had a minimum of 150 beds.

Facility A - The first facility was a 276-bed, Ukrainian Catholic facility. The facility was "non-proprietary", which means that the facility is owned and operated by a municipality or by a non-profit corporation or organization (Government of Manitoba, 2002). This particular personal care home provides personal care to individuals who require some degree of long-term care in a twenty-four hour supervised setting. Direct care providers include: Health Care Attendants (68% of all staff), Registered Nurses (17% of all staff) and Licensed Practical Nurses (7% of all staff). Other employees of the facility include Recreation Workers, Social Workers, Pastoral Care and a Registered Dietician. The majority of funding for this facility is received from the Winnipeg Regional Health Authority (WRHA), with some funding is obtained from resident per diems.

Facility B - The second facility was a non-proprietary 487-bed long-term care and rehabilitation facility providing a variety of in-patient, out-patient and outreach programs to the community. The facility serves adults with complex needs who require rehabilitation and specialized care for long-term health concerns. Funding is received through the operating division of the WRHA. Residents receive care from different levels of direct-care providers with usual staffing patterns per unit to be: registered nurses 20-33%, licensed practical nurses 14-17% and health care attendants 50-66%. All other disciplines are represented by very small percentages with the exception of Recreation, which has approximately a 0.8 equivalent full time (EFT) position on each personal care unit. The facility is comprised of eight designated personal care home units; three assessment and rehabilitation units; one psychogeriatric unit; one respiratory chronic care unit and two general chronic care units. The personal care home units (n = 8) served as the research population and are further categorized to include interim placement units (n = 2) that provide care to residents waiting for permanent placement in a Winnipeg personal care home, the units (n = 5) that already serve as permanent placement for residents and the dementia care unit (n = 1).

Registered nurse experts (n = 10) were recruited from the two facilities (5 nurse experts per facility). All nurses working in each facility who provided care to personal care home residents were approached to participate in Phase I of the study (the process whereby nurse experts were nominated by their peers).

Participant Recruitment Procedures

The study involved two phases. Phase I of the study involved the identification of nurse experts in care of the dying by their nursing peers. Phase II involved interviewing the experts identified in Phase I regarding care of the dying.

Phase I: This was the "nomination phase" of the study and was concerned with nurses identifying those nurse colleagues with whom they work and whom they deem to be experts in care of dying elderly residents. All registered nurses employed either full-time, part-time or casually on the nursing units that were targeted in each of the two facilities were invited to participate in this first phase of the study, wherein they were asked to anonymously nominate from amongst their colleagues "experts" in care of the dying personal care home resident.

The inclusion criteria of the registered nurses who were eligible to be nominated was current involvement in the delivery of direct patient care to elderly residents. While previous similar studies only included participants with three years (Helwar, 1994) or five years of experience (Hawkins, 1995; McClement, 1993), this researcher chose to not specify the number of years of experience required by a nurse in order for him/ her to be considered an expert in the care of dying residents in the personal care home. Rather, the researcher preferred to permit nurses to identify the expert nurses in their facilities based solely on the palliative care descriptors of expert nurses on the nomination form.

The nomination form that was used to guide nurses in the identification of expert nurses in the personal care homes with whom they work, was based on a modified form of the tool developed by McClement & Degner (1995). McClement's tool was based on: (1) Benner's (1984) descriptions of the attributes of nurse experts, (2) research by Hiss, McDonald and Davis (1978) that identified physician educational influences in small community hospitals, and (3) descriptions of optimal nurse behaviours in the delivery of terminal care from the critical care literature. The revised tool used in this study merged Benner's descriptors of nurse experts with particular nursing skills identified in the literature as important to care for the dying elderly in the personal care homes from the perspectives of both residents and families.

The tool consisted of three paragraphs (Appendix A). The first paragraph provided a description of nursing expertise as it related to facilitating the transition for dying residents from curative to palliative care. The second paragraph related to nursing expertise in meeting the needs of dying residents and their families. The third paragraph examined expertise as it related to nurses' communication with residents who are dying and their families.

Nurses employed by the two personal care homes that participated in this study were invited to read each of the three paragraphs on the nomination form, and then to anonymously write down in the allocated spaces, the names of up to three nursing colleagues who best fit the descriptions provided. It was acceptable to name the same nurse for more than one paragraph. Nurses were also able to nominate themselves if they believed it to be appropriate.

Phase II: In Phase II, a purposeful sample of registered nurses was recruited from the list of individuals generated by their peers in the first phase of the study. Ten nurse experts identified by their peers (5 per institution) were then sent an "Invitation to Participate" in the second phase of the study (Appendix E).

Procedure

Following ethical approval from the University of Manitoba Education/Nursing Research Ethics Board, the researcher obtained site access approval from the two personal care home facilities targeted for this study. The researcher wrote letters to the Chief Executive Officers (CEOs) of the two facilities to explain the research project and to obtain written permission to conduct the study. The researcher followed the advice of the CEOs/ designate as to the most advisable method of accessing the facilities' registered nursing staff on the targeted nursing units.

Phase I:

Facility A - Once approval for access to the registered nursing staff was obtained from this facility, the researcher began the process of recruiting participants. The researcher met with the majority of registered nursing staff from the facility at one of their monthly staff meetings. An oral presentation describing the study and an explanation of the tool designed to nominate nurse experts was provided. The voluntary nature of participation in the first phase of the study was emphasized. Nurses in the first phase of the study were not required to sign a consent form. Rather, the written disclaimer on the tool was explained and the nurses then invited to complete the nomination ballot. A ballot box to collect the nomination forms was left in the nursing office – a location identified by the nurses as convenient for them.

Additional copies of the disclaimer/ tool, as well as a one-page summary of the research study (Appendix D), were left near the ballot box for any nurses who required an additional form or information. All copies of the disclaimer/ tool were numbered and initialled in ink by the researcher. With the assistance of the Program Manager from Facility A, a copy of the information form and a nomination form were addressed to each registered who missed the researcher's presentation. Staff nurses were invited to tell their colleagues about the study, and were invited to contact the researcher if they have any questions before completing the ballot. Nurses were be asked to place their completed nomination forms in the designated ballot box, which the researcher collected two weeks following the presentation at the facility. Those registered nurses identified by the participants in the first phase of the study served as potential participants recruited for Phase II.

The names of the nurses nominated by their colleagues on the expert identification tool were listed and the number of times each nurse on the list was identified by their colleagues was tabulated. The researcher was able to cross-reference the list of names of nurses to the facility's staff list to ensure that nurses nominated by their colleagues were registered nurses. The five nurses nominated most frequently by their nursing peers in Facility A became the population of nursing experts invited to participate in the second phase of the study.

<u>Facility B</u> - Once approval for access to the registered nursing staff was obtained from this facility, the researcher began the process to recruit participants. The facility assigned a Site Facilitator within the facility as a resource to the researcher. The

researcher met with the personal care home unit managers at one of their monthly staff meetings. An oral presentation describing the study and an explanation of the tool designed to nominate nurse experts was provided. The unit managers were asked for their guidance regarding the best way to communicate information about the study to registered nurses on the personal care home units of the facility. The voluntary nature of participation in the first phase of the study was emphasized and unit managers suggested that each registered nurse be provided with an personally addressed envelope containing: i) a copy of the disclaimer/ tool, and ii) a one page summary of the research study. All copies of the disclaimer/ tool were numbered and initialled in ink by the researcher. The researcher provided the Site Facilitator overseeing the research project with enough envelopes containing the aforementioned documents for all registered nurses on the personal care home units in the facility and enough one-page "posters" announcing the study to nurses as that one poster could be placed in the conference room on each personal care home unit. Unit managers obtained enough envelopes from the Site Facilitator to ensure that each registered nurse who worked on the unit would receive one. Unit managers personally addressed each envelope to a registered nurse on the unit. A ballot box to collect the nomination forms was left in the nursing coordination office – a location identified by the unit managers as a location convenient for the nurses. Additional copies of the disclaimer/ tool, as well as a one-page summary of the research study (Appendix D), were left near the ballot box for any nurses who required an additional form or information. The researcher returned to the facility three weeks later to obtain the ballot box and completed nomination forms. The ballot box contained only one completed ballot.

The researcher, in consultation with the thesis advisor discussed alternative approaches to recruit more participants for Phase I of the study. One identified option was that the unit managers on the personal care home nursing units complete the nomination form. This was discussed as an appropriate option because the unit managers were going to be asked to ensure that that only the descriptors on the nomination form were used to nominate registered nurses. After discussing a number of options, the researcher contacted the Site Facilitator and discussed the most appropriate next step to obtain more completed ballots. The Site Facilitator felt that utilizing the unit managers was the most feasible option. The Site Facilitator met with each personal care home nursing unit manager, provided them with a nomination form and requested them to follow the descriptors on the nomination form to nominate nurses who they felt best fit the paragraphs on the nomination form. Unit managers were asked to put completed forms into a sealed envelope, which was collected by the Site Facilitator on a specified date. The Site Facilitator then provided the researcher with the envelopes containing the completed nomination forms. The names of the nurses nominated by their colleagues on the expert identification tool were listed and the number of times each nurse on the list was identified by their colleagues was tabulated. The five nurses nominated most frequently by their nursing peers in Facility B became the population of nursing experts invited to participate in the second phase of the study. The researcher was unable to obtain a list of names of nurses from Facility B, and therefore the researcher verified with those nurses who agreed to participate in Phase II of the study and prior to the interview, that they were registered nurses.

Phase II:

Following a review of the returned completed disclaimer/ tools, the researcher tabulated the number of times that a nurse was nominated as an expert. The names were then ranked according to the number of times that each nurse was named for a descriptor on the disclaimer/ tool. In the event of a "tie", where the number of times that a nurse was nominated by her colleagues, was equal to the number of times another nurse(s) were nominated in the facility, the names of nurses who received the same number of nominations were put into a hat and then pulled out randomly to determine their rank order on the list. The top ten expert nurses (5 from each facility) were sent an Invitation to Participate (Appendix E) in a personal interview. Invitations were placed in sealed, confidential envelopes, each addressed to the ten nominees. The invitations were then placed into two large envelopes, each addressed to the facilities where the nurses were employed. The individual invitations were routed to each nurse through each facility's inter-departmental mail system. Nurses were asked to indicate on the invitation whether or not they wished to participate in the second phase of the study. They were then asked to return the completed Invitation to Participate in the return envelope (stamped, marked "confidential" and addressed to the researcher) that accompanied the invitation, seal the envelope, and drop the envelope into the mail. If a nurse declined the invitation to be interviewed, the next nurse on the ranked list of nurses for each facility was approached until there were 5 nurse participants from each facility. Arrangements were made with those wishing to take part for the scheduling of a face-to face interview with the researcher.

Data Collection

Data for this study were collected using the following methods: a) semi-structured face-to-face interviews; b) demographic information collection form; c) field notes generated from interviews; and d) the construction of a reflexive journal by the researcher.

a) Interviews

The most accepted method of obtaining information is through face to face interviews - the method in which interviewers meet with research participants face to face and secure information from them (Polit & Hungler, 1999). Face-to-face interviews are regarded as an extremely useful method of collecting data because of the richness and quality of the information they can generate (Polit & Hungler, 1999). Benner (2001) asserted that it is not possible to recapture from the experts in explicit, formal steps, the mental processes or all the elements that go into their expert recognitional capacity to make rapid patient assessments. This is because experts tend to see things as a “gestalt” as opposed to viewing them in more fragmented discrete ways. This highlights the importance of inviting experts to describe their practice in a narrative, unstructured fashion through a more open-ended or minimally structured interview process.

According to Streubert and Carpenter (1999), most qualitative studies rely almost exclusively on unstructured or loosely structured methods of data collection. Qualitative researchers often use a semi-structured interview approach in an attempt to keep structure at a minimum during the interview process. Semi-structured interviewing collects data from individual participants through a set of open-ended questions asked in a specific order (Mayan, 2001). This is because semi-structured interviews provide the opportunity for greater latitude in the answers provided (Streubert and Carpenter, 1999). To ensure however, that a pre-determined set of topics is addressed in the interview with each participant, researchers often follow an interview topic guide (Polit & Hungler, 1999).

A semi-structured interview guide based on previous studies examining expert care of the dying in other settings (Harbeck, 1995; Hawkins, 1995; Helwar, 1994; McClement & Degner, 1995) and the geriatric palliative care literature, was used to develop an interview guide for the present study (Appendix B). Questions on this guide were further developed and refined as data collection and interviewing proceeded over the course of the study. Individual interviews took place at a time and location of each participant's choice. Six interviews took place in the participants' own homes while the remaining four interviews took place within the facility in which they worked. Interviews ranged from 45 minutes to 2 hours in length. All interviews were audio-taped.

Prior to beginning the interview with each participant, the researcher attempted to gain rapport by providing the participants with a description of the study and outlining the interview process, including the estimated length of the interview, the purpose of the research and that their participation in the study would be kept confidential. Participants were reminded that during the course of the interview, they could ask questions at any time and that they could choose not to provide an answer for any of the researcher's questions. They were also reminded that they could withdraw from the study at any time without any consequence. Participants were advised that the interview would be tape-recorded and that in addition to the researcher referring to a list of prepared questions to guide the interview, the researcher would be taking notes during the interview to serve as reminders of points regarding further clarification during the course of the interview.

To begin each interview, participants were asked to complete the demographic data collection form and to describe the personal care home facility and nursing unit where they are employed. Interviewing commenced using "grand tour questions". According to Polit and Hungler (1999), grand tour questions are broad questions asked to gain a general overview of a phenomenon, on the basis of which more focused questions are subsequently asked. Therefore, questions become more specific as the interview progressed, with the use of probes, as necessary to encourage the participant to provide additional detail and depth to their responses.

b) Demographic Data

The Demographic Data Collection Form used in this study was adapted from the work of Benner (2001) and McClement & Degner (1995) – (Appendix C). Demographic data was collected in order to obtain specific pertinent details about each study participant. The collection of such data enabled the researcher to describe the characteristics of the sample.

c) Field Notes

The researcher took brief notes during the course of the interview, which were elaborated upon after the interview was done. Such "field notes" are the most common form of recording information and describe the researcher's reflections, feelings, ideas about what is observed (Mayan, 2001). Field notes in the present study served to record such information as the contextual features of the interview (e.g. date, time place, location, any other facilitating or constraining things related to the interview), as well as the researcher's own personal reactions to the interviewee and the subject matter discussed.

d) Reflexive Journal

The researcher also kept a journal, which included a description of and her reactions to each interview experience. Reflective journals are narratives which are recorded by the researcher for the purpose of revealing the researcher's thought processes, as well as what the researcher views as significant (Paterson, 1994). Use of such a journal provided the researcher with a means for debriefing following potentially emotionally draining interviews with participants who reflect on their caring for dying individuals. The reflective journal also assisted the researcher in the identification of themes that emerged from the interactions with, and information obtained from, the study participants.

Data Analysis

The demographic data collected from participants taking part in the second phase of the study were analyzed using descriptive statistics. A transcriptionist hired for the study transcribed all tape-recorded interviews verbatim. The researcher then examined the transcripts line-by-line to identify key words and patterns in the data. Code words, used to identify key concepts in the data, were colour-coded directly onto the electronic versions of the transcripts. The data were analyzed using constant comparative content analysis. According to Streubert and Carpenter (1999) this involves the researcher coding the data, and then comparing them with other data from the study for the purpose of assigning the coded data to clusters or categories according to an obvious fit. Categories therefore, are coded data that seem to cluster. The researcher then compared each category with every other category to ensure the categories were mutually exclusive (Streubert & Carpenter, 1999).

Key themes and patterns were identified through the process of open coding, and the data were then interrogated and systematically explored to generate meanings. The work of Coffey and Atkinson (1996) served as a guide for this endeavour. Coffey and Atkinson (1996) described that the transition from coding the data to interpretation has a number of discrete levels: (1) the coded data need to be retrieved, which means that the reconceptualized data need to be displayed in such a way that they can be read easily, (2) the researcher explores the codes and categories that were created and abandons, changes, re-sorts and renames them so that chunks of data are not ignored simply because they do not seem to "fit" into the codes, (3) the coded data are transformed into meaningful data. Coffey and Atkinson (1996) state that while theorizing is integral to analysis, the two concepts are not separate stages in the research process, and they provide step by step details for analyzing and theorizing in order to develop ideas. At the end of the data analysis process, the researcher had an inductively generated list of nursing behaviours deemed critical in the care of dying elderly residents in the personal care home setting, from the perspectives of nurses providing such care. The researcher shared a random sample of some of the interview transcripts, list of codes and coding procedures with the thesis advisor. The thesis advisor also provided assistance in the clustering and reorganization of categories and sub-categories. Operational definitions were written for all major categories emerging from the analysis.

Steps to Ensure Rigor

Qualitative researchers want to ensure that their findings are credible, dependable, confirmable and transferable (Guba and Lincoln, 1994). Credibility (internal validity) includes activities that increase the probability that credible findings will be produced (Lincoln & Guba, 1985). According to Streubert and Carpenter (1999), credibility is demonstrated when participants recognize the reported research findings as their own experiences. "Member checks", are an identified method of assessing the credibility of data in qualitative research (Lincoln & Guba, 1985; Tri-Council Working Group, 1996). Lincoln and Guba (1985) describe this exercise as verifying the findings with the research participants themselves. Member checks have been recommended in recent ethics guidelines (Tri-Council Working Group, 1996). The researcher performed member checks in two ways during the course of this study. First, provisional verification of the issues and ideas being raised in the interview were addressed through such interactions with participants at the end of the interview as: "What I hear you saying about providing expert care of the elderly person dying in a personal care home is......" or "It seems to me that you have identified these behaviours as important in care of the dying elderly person, have I got that right?" Second, once data were analyzed and major themes and codes established, the researcher provided participants with the opportunity to review a summary of the findings. The researcher telephoned each participant to invite their feedback and critique regarding the extent to which their ideas and experiences have been captured. Participants were given the choice of meeting with the researcher in-person, or completing the review over the telephone. All participants who participated in the member-checks opted to discuss the summary of the preliminary findings over the telephone. Six of the ten participants participated in the member-checking procedure. Two participants did not return the researcher's telephone calls and two participants were out of town. As a final check on the validity of the inferences being drawn from the data, the preliminary draft of this chapter was reviewed with the participants in this study for their feedback and suggestions. No changes or revisions were as a result of the consulting process.

Dependability is a criterion met once researchers have determined the credibility of the findings (Streubert and Carpenter, 1999). Dependability (reliability) in qualitative measurement may be addressed by providing a clear description of the methods utilized in recording data and the use of verbatim accounts of interviews or direct quotations in the field notes (Rowan & Hutson, 1997). All interviews were tape-recorded and transcribed verbatim by a transcriptionist. Where appropriate, documentation of the findings included direct quotations from participants. Streubert & Carpenter (1999) stated that participants' experiences are the findings of qualitative research and that it is therefore, essential that the experiences be reported from the perspective of the people who lived them. The inclusion of quotations adds to the richness of the reported information and to the understanding of the social interactions experienced by the study participants (Streubert & Carpenter, 1999).

Confirmability is a process criterion (Streubert & Carpenter, 1999). This means that the way a research study is conducted, particularly the specific details of the study's methodology, contributes to confirmability. Streubert and Carpenter (1999) stated that the way researchers document the confirmability of the findings is to leave an audit trail, which is a recording of activities over time that another individual can follow. The objective is to illustrate as clearly as possible the evidence and thought processes that led to the conclusions. It should be noted however, that despite including such detail in the documentation of the study findings, another researcher may not agree with the conclusions developed by the original researcher (Streubert and Carpenter, 1999). During the data analysis portion of this study, the researcher documented all key words or codes (which will be discussed in more detail in the following section) directly on the interview transcripts. The coding procedures were recorded and the subsequent lists of codes, needed for identifying categories later on in the analysis procedure, were also noted. The researcher documented all major decision points in the study, and all of this information was stored with the data.

Transferability refers to the probability that the study findings have meaning to others in similar situations (Streubert & Carpenter, 1999). Establishing transferability may be achieved through the use of triangulation, a means of obtaining an accurate representation of reality through the use of multiple methods or perspectives to collect and interpret data (Polit & Hungler, 1999). A key factor in the transferability of data is the representativeness of the informants (Krefting, 1991). Krefting (1991) stated that one strategy used to address transferability in sample selection is the use of a panel of judges to help in the selection of informants representative of the phenomenon under study. It is hoped that the process of inviting all personal care home nurses in each of the two sites to identify expert nurses in the provision of end of life care increased the transferability of the data. The researcher utilized "space triangulation", which consists of collecting data at more than one site (Streubert & Carpenter, 1999). Streubert and Carpenter (1999) stated that triangulation also contributes to the completeness and confirmation of findings necessary in qualitative research investigations.

Ethical Considerations

Protection of Human Subjects

Human rights were protected in this study in the following manner:

1. Ethical approval to carry out this study was obtained from the University of Manitoba Education/Nursing Research Ethics Board. Site approval was obtained through direct contact with each of the two sites chosen for this research project.
2. All phases of the study were explained to potential participants both verbally and in writing. Participants in all phases were provided with contact phone numbers of the researcher, and her thesis advisor in the event that they had questions or wished to discuss any concerns regarding the study.
3. Those nurses who agreed to participate in the first phase of the study and identified expert nurses in the field remained anonymous. The researcher advised participants to not put their names on the expert identification tool.

4. All nominees who accepted the invitation to participate in the second phase of the study were advised both verbally and in writing that their participation was voluntary and that they could withdraw from the study at any time.
5. Participants were asked to complete a signed consent form (Appendix F), and completed forms were stored in a locked cabinet in the researcher's office, separate from the transcribed interview data. All participants were assigned a code number. This code number was used in place of individual names on all data collection forms, and in field notes. Names, and other identifying information occurring during the interview were replaced with pseudonyms at the time of transcription.
6. In addition to written consent being obtained from participants in the second phase of the study, the concept of "process consent" was also incorporated into this research. This approach requires that researchers, at varying points in the research process, re-evaluate participants' consent to participate in the study (Streubert & Carpenter, 1999). According to Munhall (1988), the static, past-tense of informed consent does not adequately protect human subjects in qualitative studies. Informed consent must actually be an ongoing process. Munhall (1988) stated that qualitative research is conducted in an ever-changing field and therefore consent needs to be renegotiated as unexpected events or consequences occur. Process consent is a method for continually informing and asking

permission, which establishes the needed trust to go on further in an ethical manner (Munhall, 1988).

7. During the interviews with participants in this study, it was anticipated that for some participants reflecting on situations that involved the deaths of residents in their care would be difficult and emotionally draining for them. By asking participants to recall and describe situations that were likely emotionally powerful times for the nurse providing care to the dying resident and their family, it was understood that this may place participants in a vulnerable situation and stir up emotions that have not been realized for some time, if at all, in the past. The researcher anticipated that extra time spent with some participants would be required to acknowledge the participants' feelings and provide necessary support. According to Streubert and Carpenter (1999) allowing time for feedback and discussion of participants' feelings brings with it the possibility that the researcher will hear too much, but it must be done. Participants were also reminded of their option to terminate the interview at any point if they found that the discussion taking place was too distressing. In the course of interviewing nurses, three participants become teary-eyed as a result of the discussion that was taking place. In all three cases, the researcher offered to turn the tape-recorder off. One participant exercised this option and the recorder was turned back on following her composing herself and her indicating that the recorder could be turned back on again. In all situations,

the researcher provided participants with facial tissue and provided emotional support.

Summary

This chapter has provided an overview of the methodology used in answering the research questions posed in this study. The sample and setting for the study were described, and data collection and analysis approaches discussed. Steps that were taken to ensure the rigor of the study were presented. Ethical considerations inherent in conducting the study were identified.

CHAPTER FIVE

FINDINGS

This chapter will report the findings of a qualitative study conducted to delineate expert nurse behaviours in the provision of end of life care to elderly residents dying in the personal care home setting. The characteristics of the sample will be described, and the 10 critical nurse behaviours that emerged from content analysis of interview transcripts with nurse experts will be presented. Data exemplars will be provided to illustrate the behaviours that were identified. In order to ensure the participants' anonymity, all names in the exemplars have been replaced with pseudonyms. Final descriptions of the 10 nursing behaviours that emerged from the study, along with their operational definitions are presented in Table 2.

Participant Recruitment

In Phase I (nomination phase) of the study, six completed disclaimer/ tools were retrieved from the ballot box from Facility A. From the completed tools, 11 registered nurses were identified at least once by their registered nurse colleagues as best fitting a descriptor on the tool. The names of the 11 nurses were listed in rank order according to the number of times they were named for a descriptor. The top five invited to participate in Phase II (interview phase) of the study. One nurse declined the invitation, and therefore, the sixth nurse on the ranked list of nurses from Facility A was invited to participate in an interview.

As identified in the Chapter Four (methods section), only one completed disclaimer/ tool was retrieved from the ballot box from Facility B. Following the second attempt that was subsequently utilized to obtain names of expert nurses in Facility B, five more completed disclaimer/ tools were obtained. From six completed tools, 11 registered nurses were identified at least once by their registered nurse colleagues as best fitting a descriptor on the tool. The names of the 11 nurses were listed in rank order according to the number of times they were named for a descriptor. The top five invited to participate in Phase II (interview phase) of the study. Two nurses declined the invitation, and therefore, the sixth and seventh nurses on the ranked list of nurses from Facility B were invited to participate in interviews.

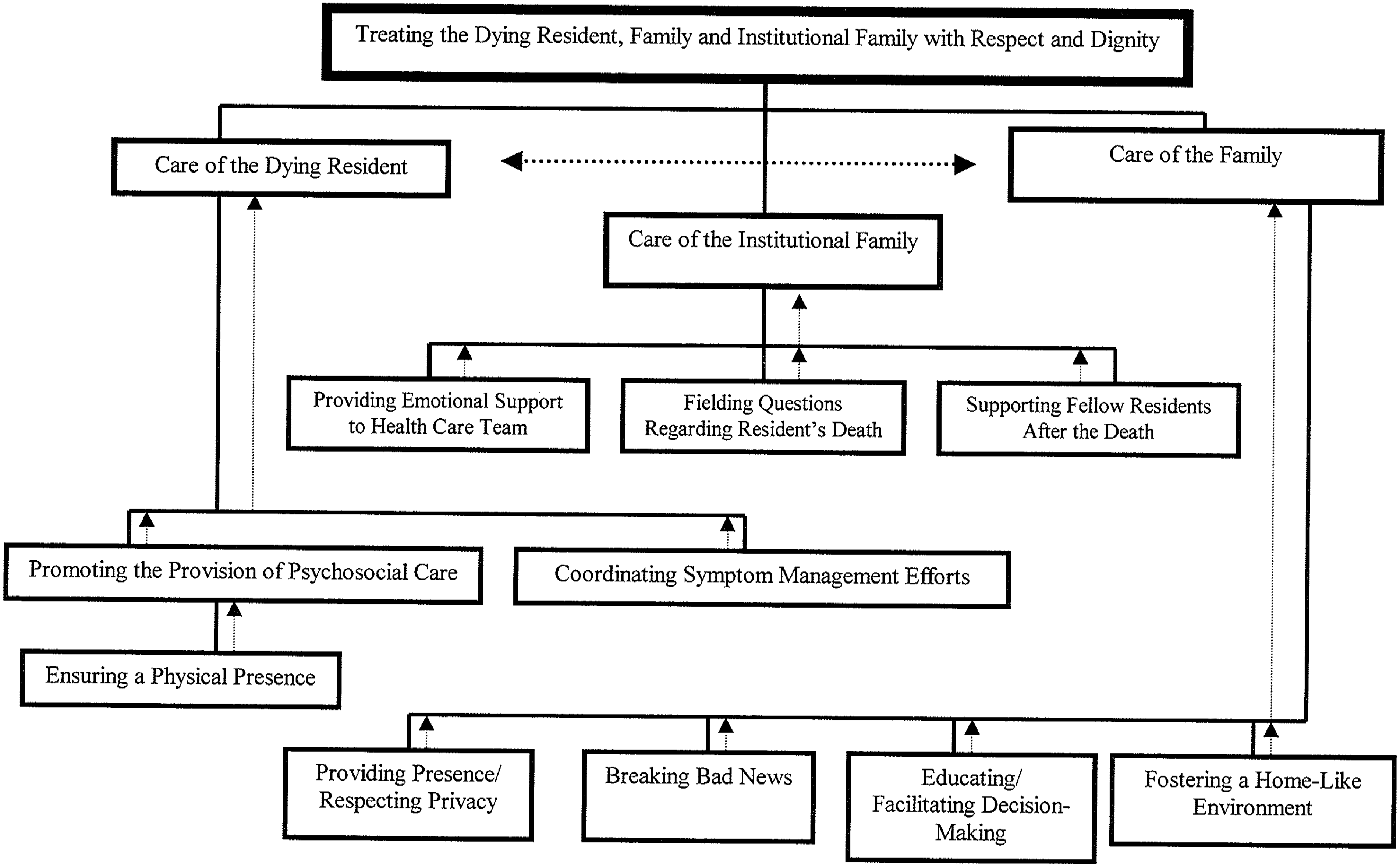
Characteristics of the Sample

A purposive sample of 10 personal care home nurses identified as "expert" by their nursing colleagues in the care of dying residents participated in this study. The characteristics of the sample are summarized in Table 3. Participants ranged in age from 43 to 61 years, with the mean age being 52.5 years. All participants were female. Participants had an average of 29.4 years of experience as registered nurses, with years of individual experience ranging from 15 to 40 years. The average number of years of personal care home nursing experience was 12.5 years, with experience ranging from 10 months to 25 years. In terms of nursing education, eight participants had obtained a registered nursing diploma with the remaining two participants holding baccalaureate nursing degrees. Only one nurse, who had been diploma-prepared, identified herself as having completed a post-basic/ specialized palliative care course.

Critical Nurse Behaviours in Care of the Dying Elderly Resident in the Personal Care Home

Three major categories of nurse behaviours in care of the dying elderly resident in the personal care home emerged from the data. They include: 1) Care of the Dying Resident; 2) Care of the Dying Resident's Family; and 3) Care of the Institutional Family. A framework summarizing the behaviours is outlined below in Figure 4. Operational definitions for each of the major categories, and the specific nursing activities subsumed under each category are summarized in Table 2. This chapter will provide a description of each of the major categories and sub-categories identified by participants in the study, supported by data exemplars.

Figure 4: Critical Nurse Behaviours in the Care of Dying Elderly Residents



Care of the Dying Resident:

Care of the dying resident emerged as a major category in this study. Interviews with expert nurses regarding care of dying elderly residents revealed three specific behaviours related to this category. These included: i) promoting the provision of psychosocial care and ii) coordinating symptom management efforts.

Promoting the Provision of Psychosocial Care

Nurses were responsible for promoting the provision of psychosocial care to dying residents. Promoting of the provision of psychosocial care included the nurse displaying behaviours that not only ensured a resident's physical/ or symptom management needs were addressed, but ensured that emotional needs were met as well. In order to meet a resident's emotional needs, nurses used touch, and attended to his/her spiritual needs:

> Jan: "To be close to a resident, to hold their hand, a patient, to hold their hand and to not to be afraid of touching them and to care for them and to just say a prayer or words of strength and to let them know that somebody is there that they are not dying alone. It's spiritual with the prayer and the caring. It's okay to cry and it's okay to you know, be around even though you think that they don't hear, but they hear or they know, some senses are still there, they know that somebody is present. And that is a big comfort and you see in their face that it's more relaxed. You know, rub her arms or her back or to do something, do her hair, something she would enjoy, that she enjoyed in the past. You know she was able to say, to tell them what if fact she didn't want

> anything done, too tired, or whatever, but you often would find them relaxed and eyes closed when it was being done and stuff like that, because it's very therapeutic. Your physical [care] is one thing but, I think, it depends on how you look at spirituality, I think nurses work, we do lots of tasks, but it's the spiritual, it's the caring and the hands touching people and that's comforting and therefore, to me is spiritual work and in the dying we'll say prayers and we'll comfort and you know, rub their forehead with a wet face cloth, or wet their lips or things like that, is, is um, is spiritual in just doing these physical things."

Nurses indicated that in providing care to dying residents and their families, they often encountered angry or dysfunctional families. In promoting the provision of psychosocial care, nurses often advocated on the resident's behalf and attempted to protect the resident from being burdened by and caught up in difficult family dynamics that occurred at the bedside:

> Mary: "You know, there are a lot of broken, dysfunctional families, this one's not talking to this one…for whatever it's worth let's look at this as a family and let's give Mom permission to go and let her see us as a united family and not squabbling, fighting, because then she goes in peace. I've seen family members where this one couldn't come and visit until this one leaves and this one…can you imagine the turmoil for that person in there. And people don't um, they don't come together, they don't think that Mom is leaving, you know."

> Jan: "He [the resident] had an interesting history where he had married, separated when the children were very young, I think he had three or four children, ah, and his wife had the children and he never had contact with his children and one daughter phoned um, and he wasn't well and we expected you know him dying and ah, it was his wish he didn't want to be treated and anything like that but I had spoken to the daughter, I'd never seen her and she said oh well, maybe after Christmas I will come and visit my father, I haven't seen him in ages."

Nurses commented on how challenging it was for them being involved in situations where there were poor family dynamics. Such dynamics made it difficult, if not impossible for nurses to assist these family members to be more supportive of one another, or to improve the situation for the resident:

> Michelle: "There were horrible family dynamics as well, so if she was there, then the other sister couldn't come and that kind of stuff. So that was very difficult because when family can support each other and you're there just as a, sort of a lynch pin to the system you know, usually it's very satisfying to be able to answer their questions, but boy when you're caught in the centre of that kind of family, bad family dynamics it's awful."

> Anne: "A lot of times its like families. Like the one I mentioned earlier, the dysfunctional family that um, you don't have enough people to help you to deal with them plus the resident, keeping them comfortable. And especially

> when you're looking at someone who you know, respiratory, you know short of breath, and, and you really need to provide a lot of hands on medical care at the time. Um. And then you have the family that is just, you know, obviously in need as well and, how do you split yourself?"

A nursing behaviour that emerged from the findings as critical in the nurses' provision of psychosocial care for the dying resident that seemed particularly significant to nurses is that of ensuring a physical presence at the resident's bedside. This behaviour refers to specific actions on the part of the nurse to help ensure that the resident did not die alone. To this end, nurses took the responsibility of contacting the resident's family when a physical decline occurred in the resident that suggested death was near, and encouraging family members to come to the personal care home before the death of the resident, if they desired to do so:

> Michelle: "You know who I feel the sorriest for are the people dying alone. That really breaks my heart, because there are some that, there's nobody around. I think in most cases when you are welcomed to this earth you are born into a family and you know, hopefully if your life is of any, any fulfilling type of um story, the family surround you through life and then they see you out as well. So this is a nice thing about family, it is so important to have family. I don't care who you are, you know, family, friends, especially when you're dying, you need someone there, you know. You need someone, you need your family."

When it was not possible for family to be present with the resident in the final hours of his or her life, nurses attempted to ensure a physical presence at the bedside by either being there themselves, or delegating this activity to another member of the health care team (such as an HCA, a member of the pastoral care department). In so doing, nurses were in essence mobilizing the resident's "surrogate family".

> Michelle: "The family is the unit for that one person, yes, and I think they're the ones who should be there and if there is nobody then I think we should be with them. You know like, there should be somebody with them."

> Carrie: "I don't like to see them die alone. If we know that somebody's alone we try to be there with them. And have someone sit with them."

That family members acknowledge and appreciate the role of staff as surrogate family in the personal care home setting was identified by study participants:

> Sharon: "Like a resident that I knew, I knew the daughters quite well. And they were both out of town. Living out of town and they would...because they knew me, and they had to move, one of them had to move. One of them lived out of town; the other one was transferred out of town. And she felt it, found it very hard to move. But she said 'I don't feel so bad because I know I'm leaving him in your care.'"

Nurses stressed that quality end of life care for residents depended more on the personal nature of the care that staff delivered, as opposed to the nature of the physical surrounding in which care was delivered or the types of treatments being provided:

> Michelle: "Some residents when they come here they know that this is the last place. They know and they don't say they come here to die, some people will tell you 'I couldn't manage myself', they put it in that kind of manner: 'I cannot manage at home so I have to come here to be looked after'. But some people who project a little bit more will tell you 'I came here to die - this is my last place. I know after here I'm going to die.' Just knowing that you're there maybe is enough for him. I think it's what you practice. It has nothing to do with the building, it has nothing to do with the place, it has nothing to do how organized you are with your morphine and what regime you have. It's what you have there and if your team, if they're capable of looking after the dying. That's how I look at it."

Coordinating Symptom Management Efforts

In addition to ensuring a physical presence at the bedside, another behaviour nurses identified as being important in care of the dying resident was that of coordinating symptom management efforts. This behaviour refers to the nurse's actions directed at reducing the resident's physical and psychological suffering. An important aspect of this behaviour involved the nurse assessing for the presence of any physical symptoms the dying resident was experiencing:

> Sandra: “This person needs us now, let’s go in and assess and see what does she, what does she need, is she comfortable, does she have a temp, is she in pain, you know, mouth care, um, make her comfortable and then we can go to the other people and take care of them too.”

While nurses conducted their own assessments of patients to detect evidence of symptom distress, they also relied on information provided to them by other members of the health care team about this issue. The nurse oversees the care of the dying resident that is delivered by health care aides, and in this way, acts as the point person on the unit for receiving the report of any changes to the resident’s health status. Other members of the heath care team brought their concerns regarding residents to the nurse, the leader of the care team, for her consideration and to determine the plan for next steps:

> Michelle: “The HCA’s are all coming to you with, they noticed this, there’s that and they need this, so I mean besides doing what you have to do and administering your meds you’re always running to check and you’re sort of filling the gaps for them and you know…”

While nurses did depend on information the health care aides communicated to them, it was evident from the experts interviewed for this study, that they were more comfortable assessing a resident’s status for themselves first hand:

> Lori: "I never go by what the shift before me has told me. Always, always, evaluate the situation myself. That's the first place [the resident's room] you go."

Nurses indicated that their assessment data provided the foundation from which to begin to craft a plan of care to address symptom management issues that were present:

> Michelle: "So I'm making sure that I'm, that he is comfortable and if there is anyway I can give him, like give him some oxygen, if I can give him something for pain, just to help him or, to help him through um, through this process of death."

> Anne: "She [the resident] was guarding and all the [non-verbal] signs and symptoms of pain were there. And then after, after taking, you know having her analgesic scheduled properly, she was able to, she was able to move, you know you could move her without those [non-verbal signs of pain]."

In addition to assessment, planning, implementation and evaluation, an integral part of coordinating the patient's symptom management involved the nurse "going to bat" or acting as an advocate for the patient in the area of symptom control. Sometimes, advocacy meant nurses pushing physicians to seriously address symptoms residents were experiencing:

> Anne: "Because sometimes you need to uh, on our floor we only do so many, like there's, there isn't IVs and there isn't um IV meds of course and any of those type of things, so you've got to look okay, okay what type of comfort can we provide on our floor, if that's what they want we've got to make sure we have that available. So then we're their advocates in a lot of ways because um, sometimes you'll hear people saying, okay they're older now, we're not going to be aggressive with them. And so we have to say okay just a minute. This is something that can be treated for this individual. Let's try some treatment. You see, we're their advocate."

In contrast, sometimes advocacy meant nurses vocalizing their concerns to physicians and/or family members about the implementation of interventions nurses believed were not in keeping with the resident's wishes regarding end of life care, and/or which posed significant burden and minimal benefit to the resident.

> Jody: "You know I think that you've got to go to bat for the resident even though sometimes what you know is best for them is completely opposite to what the family wants…he [the resident] was comfortable. We're all in there back and forth as often as we could be. And I, you know, you're just there to support them."

Nurses in this study often viewed the transferring of dying residents out of the personal care home to a hospital to receive interventions as something particularly burdensome, and thus advocated to keep the resident in the familiar surroundings of the personal care home to die:

> Michelle: "So I remember spending quite a while with him [the son] asking, you know, like, sort of explaining to him that it [transfer to hospital] was probably more for himself not for her. Otherwise he would have wanted her sent to the hospital and there was just no point in doing that to that poor little thing you know. It was the end of her life."

> Lori: "I think in uh, in the nursing homes and personal care homes, there's a lot more personal touch with the staff. I think it's because um, that is their home and, and as I say we see these people constantly. And we keep them at home as we call it. To, to die and to have their last comfortable moments in familiar surroundings in their own room with all their own belongings. Their own pictures and everything."

The ability of the nurse to be able to act as an advocate for the resident presupposed that she was aware of what the wishes of dying residents were concerning their plan of end of life care:

> Anne: "You know. So. Or often they'll [physicians] ask us: 'Well, what do they want?' And so then we need to have, um, talk to the family to know what the family's uh, decisions are, and also their advance care directive."

> Anne: "[It was] difficult because then you felt um, he died at the hospital. But you kinda felt that it kinda left you uh in limbo in the fact that, you didn't get to provide that last care. But that was his wishes so that's what you have to go with."

Nurses also interacted with other members of the health care team in coordinating symptom management efforts. Nurses interacted with all members of the health care team including licensed practical nurses, health care aids, social workers, spiritual care providers, recreation workers, housekeeping staff and physicians. In coordinating symptom management, nurses were frequently involved in educating other members of the health care team, particularly those with a lower level of health care education, about the provision of care to dying residents. Sometimes, this education involved explaining reasons for changes in the resident's physical condition:

> Mary: "We have some HCAs, who I don't know if they don't recognize or don't recognize that or even do you tell them this one is dying, they don't understand it when we say someone is dying that your systems gradually shut down. They figure, oh no, you're not supposed to keep them in bed, you know, don't have them in bed, bring them out, and you know you can see the person you know really cheyne-stoking and all of that and, oh no, no, no, you get them up, you wind the bed up, um, you really want to keep those people in bed all the time, um, you know you should get them up in a chair and, are you not going to put some food in, and no matter how much you explain because

> in my job, I realize I have to go as a teacher. And, because I know I'm expecting them to go there and do a job, in order to do it and for them to understand what's going on I explain a lot to them. Educate, educate, educate."

Other times, nurses were educating members of the health care team about the importance of demonstrating behaviours that were sensitive to, and respectful of, the fact that family members were dealing with impending loss:

> Jan: "I think it's more mechanical, you know, where um, they [the HCA's] may be laughing about something and I've taken them aside and mentioned, 'you know, with the family standing outside be very sensitive. Like you are looking after somebody that's dying you know and an outside attraction was funny but, you know while you are doing the care.'"

The previous section identified two critical nurse behaviours that were directed specifically to the care of the dying resident. The findings from this study suggest that another primary concern of the personal care home nurse in the provision of end of life care, is care of the dying resident's family. The next section presents the critical nurse behaviours that emerged from the data specific to the care of the family.

Care of the Dying Resident's Family:

Nurses indicated that dying residents' family members also require nursing care, and in many instances, the majority of nurses' efforts were directed toward the care of these individuals:

> Sharon: " Its just sort of I find you're, you're looking more after them [the family] at that point in a way and not the resident. And uh, I think they, well, really they need a lot of support deciding, making that decision - that like to have just Palliative Care. That's a very, very difficult time I think. And difficult for us too cause you lose them [the family] too."

> Lori: "We do like everything for the families. We're more in tune with the family than we are the resident. We're, we're so used to um, we are their family and we're, we're as close to the family as we are to the resident. We're with them more than we are our own families. I'd have to say 60% of my day everyday is dealing with families. And in person, on the phone, with all different aspects. And especially in end of life care you, you, you're dealing totally with the family."

As one nurse indicated, ensuring that dying residents were comfortable and well-cared for was not only done to benefit the resident. That is, caring for residents was also a way to provide care to the resident's family:

> Mary: "Do it now and when you are leaving that bed, leaving that room make sure everything's done, comb their hair, fix them up properly so when a

> family member walks in that room and they look and they say ' these are really caring people, she is comfortable.' That's, it's not the morphine that you are putting into the person, it's how they are. When they come and they see that person dying, traveling, going their way and they are at peace, you know, clothes not strangling them and the bed well made and you know, when you're going in there and you're doing things and you're not just talking...but you're looking after the person properly."

Interviews with the expert nurses regarding care of dying elderly residents revealed four specific behaviours directed towards the dying resident's family. These behaviours included: i) providing a presence/ respecting privacy; ii) breaking bad news; iii) educating family members/facilitating decision-making; and iv) providing a comfortable environment.

Participants in this study indicated that their ability to engage in these behaviours was greatly facilitated by the presence of rapport that had been developed between the nurse and members of the resident's family. Rapport was the foundation upon which effective communication was able to take place between the nurse and family, and a therapeutic relationship with the family built:

> Anne: "......the rapport that there is established [in the personal care home], one would hope the rapport is elsewhere. In acute settings you don't get that same rapport because you just don't know these individuals as well."

Providing a Presence/ Respecting the Need for Privacy

Nurses felt that it was important to provide a presence for the family when the resident was dying. Providing a presence in this way referred to both being physically present at the resident's bedside with the family as well as being available and accessible to the family. In providing a presence family members were assured that they had someone to turn to if they had questions or were in need of support. At the same time, however, the nurse also had to be cognizant of the family's need for privacy at this highly emotional time and be mindful that family members may want to express final sentiments to the dying resident and say "good bye" in privacy:

> Michelle: "Be immediately available. And I mean, sometimes I think the family don't want you right at the bedside when they are going through a time like this, but for you to be right there and to be able to answer any questions, to help them through anything, you know, just sort of provide anything need and kind of fill the gap. Yes, or to actually be there at the time of death. Sometimes family like to be private. Sort of a family, private family thing. So you know, you're closely available and if you feel that they're welcoming you there you stay, but if you feel that there, you know, there's that little bit, you just sort of step back far enough to give them some privacy."

> Michelle: "But ah, you try to just give them as much space around them but to let them know that you're there as well."

Breaking Bad News

In the personal care home, nurses are responsible for communicating bad news to family members. "Bad news" in the context of this study refers to advising a family about the worsening of a resident's condition or the death of a resident. The behaviour of breaking bad news included contacting the family to advise them of deterioration in the resident's condition or notifying family when a resident had died. Nurses used their knowledge and nursing assessments to help guide family members about whether or not and how quickly to come in to the personal care home to see the dying resident:

> Jan: "I was honest with the daughter and I had told her that you know, that if she wished to see him it might be her last chance. So that was, that was her decision then, at least she knew."

Most often the communication regarding deterioration in the resident's condition occurred over the telephone. Nursing behaviours were directed at advising family members when a resident's status had deteriorated thereby enabling the family to get to the bedside before the resident died. Such telephone interactions typically involved nurses giving family members a "warning shot" in which she described some of the physical changes she is seeing that are cause for concern to prepare them for the bad news that was to come. The following exemplars illustrate the ways in which nurses would give family members a "head's up":

> Sandra: "So I think that ah, it is important like you want to let them know that right away, like you get to know them, they would want to be here. So you

want to like, oh 'I want you, I want you to know that she's not doing well and you can, you know, decide if you want to come or not.' It is the nurse who would do the call, do the calling, saying like, 'You know I am really, really sure you know that she is sick……' like you kind of always like, oh, is she really dying, is this dying, should I call the family now. And sort of like of you say, you know maybe 'She's not responding today…..' or 'Her respirations are up and her pulse is rapid or she has a temp or um, and I feel that she's, she's not doing very well today, you may want to come and be with her' um, um, or if we know that she hasn't been doing well and we're aware that she hasn't been doing well and like this is, now this is it like maybe she's mottling and it's going to be soon and maybe they have gone home and you say, 'You know I think this is the process that she's in now that she's dying, so you may want to come and this is what's happening. I just want you to know that she has taken a turn for the worse, she's not well, she's not responding as well today. And you know, if you want to come and see her, you might want to come and see her or just so that you're aware that she's not well and that's your decision whether you want to come because maybe some people don't want to come, some people don't want to be here at the time.' So, sort of giving it to them and you can decide whether you want to come or not."

Mary: "Well, he asked me how bad her condition was if it could wait until Monday. This was a Friday and he was going to the lake, last summer. And I called him and he said um, he said, he said um, um, 'Oh I was going to the

> lake; I'll pass there before I go.' And I said that would be nice. At least, you know, he would have passed and seen her and then you're not worrying. And he told me to look out for him in ½ hour and then he didn't come. Then I decided to call again before I went home. So I called him and I said, 'You know the lake is always going to be there, but the way things are right now you just don't know, I don't know, I'm not God, I don't know time at all, I don't know when it's going to happen.' I said 'Would you not feel better to know that you came to see your Mom and you had time to talk to her?' And then, I said 'You may not be able to do anything for her, but at least you'll have had time to talk to her and spend some time. Then you can spend a nice weekend at the lake.'"

In communicating bad news, nurses understood that receiving such information can be very upsetting and has implications (both psychologically and in terms of safety) for family members who hear it. Therefore, nurses indicated that they took steps to intervene by asking if family had a person to drive them to the personal care home, or whether the family member had someone to be with them:

> Michelle: "Several times I've called to tell them that there's been a change for the worse and if you want to be here you better come. And ah, they often come and they're, you know, very, and you try and see if there's anyone else there with them so that they're not driving and that type of thing and make sure that they're safely there or they can get the neighbour to bring them."

Sometimes, the breaking of bad news involved communicating to the family upon their arrival to the personal care home facility that the patient had already passed away, prior to their arrival. Under these circumstances the nurse worked quickly to intercept the family upon their arrival to the nursing unit prior to seeing the resident. Nurses tried to prepare the family regarding what they would see in physical terms when viewing the deceased resident, and provided emotional support to the family members.

> Wendy: "So a lot of times when they come in it's already beyond the point, they've already passed on. So, as you greet them, you say, 'I'm sorry but you know, your mother just passed away' and ah, you're willing to stay [with the family]."

> Mary: "So he came up and I came out of my seat very fast and I told him who I was and I told him what her condition was, what to expect and we went in there."

In having to break bad news to families, nurses described the utility of having previous knowledge regarding family's wishes for the resident's care, particularly when the resident's condition deteriorated. The findings suggested that if the nurse had an awareness of family wishes and expectations, prior to the resident's condition worsening, the nurse can prepare herself for that when she calls them with the bad news.

Michelle: "Well, making sure that I'm following the wishes of the family if they want him, anything, you know, dramatic done, or any kind of.... You soon get to know which families are, want the ultimate treatment of everything."

Educating Family Members/ Facilitating Decision-Making

An important behaviour identified by nurse experts in this study regarding care of the dying resident's family was that of education. In particular, nurses spent time teaching family members about what to expect as the resident demonstrated physical changes indicative of imminent death:

Carrie: "The nurse was very good in explaining to the families um, exactly what was happening that their family member/loved one was dying and things that they could possibly expect to see happen, what could be, you know maybe some of the things that they were seeing. And why they were, these things were happening to that person and the things that they could expect and things that you know that she was going to do to help them and you know just to be there for them."

Michelle: "Mom was dying we were anticipating problems, you know, because they just seemed like they had a huge...and they really just, they, I don't know if they had never been intimately involved with somebody dying over a period of time and I ended up going in and talking to them several times because they had all these questions. So I spent quite a bit of time

> talking to them a couple of times and again they were very grateful because they said they just want to know what to watch for. And ah, you know you sort of explain to them that once you see the mottling progressing up their legs I mean that's a matter usually of hours and ah you know, so when they saw that happen they called all the family and they were there when she died. Mm-hmm, they wanted to know that, they wanted to know that, they wanted to know what the changes meant and how they you know like, I guess they wanted to know when to have everybody around and they did bring the family."

Nurses sometimes supplemented the verbal teaching that they did with families by using such things as printed material that the nurse had researched and photocopied for the family:

> Jan: "And for families too you know, we have to keep them well informed and why we're doing the things…And I made photocopies [of some research material that the nurse had located] and explained to families but they don't always believe you unless you back it up with research that you are doing or concrete, and writings and things like that so that's what I did, I made a photocopy and asked family members to read and to back up what I was saying. And in fact, you know it totally changed people realizing that oh well, yes, they don't want to drink and you have to respect what the person wants."

Another educational strategy nurses used to teach family members about end of life care was to model behaviours the family could engage in when interacting with and caring for the dying resident:

> Jan: "Bringing them [the family] closer when you explain to them how, um, important it is to you know, hold their [the resident's] hand, to know that somebody is there. You need to treat them you know as if you were in their shoes in that time, you know, it is important for them to know that they are not alone."

> Jan: "...you like to walk in the room with them and, and guide them. You know, I put a chair like don't sit way in the corner of the room. I would bring the chair, like I don't say that, but I would move the chair as I'm talking, right beside the loved one. And, and then you know talk a bit and when I come back yes they're sitting right there and they're holding the hand. As opposed to sometimes you walk in and they are sitting at the foot of the bed, you know, and ah, and that's something that, you know, often you have to tell family members, you know, they [the resident] know that you're here, they know you're present and that's important."

Also as a part of educating families, nurses were often in the position of having to guide families in the decisions that they had to make. In guiding family decision-making the nurse was required to share her knowledge and experience in end of life care. This included outlining care options that were available. As one nurse stated:

> Anne: "And even with some families too, they want us to give them some guidance. And some of the family members are scared to ask cause they're in that generation where they don't ask as many questions, and they're scared to ask. And scared to say well, can we try this. So, not that you're wanting to influence their decision, but you want to make sure they know the options. So just even being, informing them, and making them aware of, okay these are what things can be done, this is what it would entail, like it's not going to be aggressive but you know an antibiotic, if it would work for them."

Nurses also educated family members about end of life care options so that families were better able to weigh the potential burdens and benefits of particular treatment options available to the resident:

> Michelle: "She [the daughter] said 'I don't think I'm going to be back again, I can't stand to watch this and she said it makes you not believe in God.' So we had a bit of a discussion about that and ah she said well maybe we should have sent him to the hospital because he had gotten sick a while back and he'd gone in and had IV's for a month and he kind of got, and then he was okay for a week and then down he went again. So I kind of went through with her, like, yes you can slow it down but you know like, the periods in between getting him to a point where he seems like he's better again will be shorter and shorter because his body is simply is no longer able to keep going. And

> she seemed to understand that and ah anyway, I was glad that it was me that was on that evening to phone and tell her that he had died."

Sometimes after receiving education from the nurse about treatment options for their dying relative, family members still struggled about what decision they should make regarding the resident's care. In such instances, nurses would engage family members in a process that was designed to help them hone in on what the resident would have wanted, if he/she were able to make their wishes regarding care known. This approach utilized "substituted judgement" to help the family ensure they were making care decisions that were congruent with those of the resident:

> Jan: "No, not that they didn't care but they just couldn't make a decision on comfort as opposed to treat fully and even if you'd say well, if you sign for comfort care it doesn't mean if something happens that, you know, we would discuss with you, you can change your mind. I mean that's always open, but no some families are just, I guess they are not comfortable with making a decision. But also I think, like my philosophy is always to just make a point of asking families like to help them along: 'Have you ever heard your parent or spouse or whoever it is to you, your loved one say at one time in point during their lifetime as to their wishes?' You know, and you, they know at one time in point. If they think back most of them at one time in their lives have expressed some things that they, that they would not want. So go along with that,

> you already know their wishes when they have to make a decision for a parent. That helps them along I find."

> Jody: "I said 'what to you think your Dad would want here? What do you think your Dad would want?' 'Well we think probably Dad's ready to go you know, he's, but...' I said 'well, are you doing it [transferring to the hospital] for your Dad, or are you doing it for yourselves?' And they, you know, it wasn't a definite answer, but she came to me the next day and she said you know she said we all thought afterwards she said and it was for us that we wanted to do that. So they and you know he died very comfortably in the, in the room that he'd been in for three years."

Fostering a Home-Like Environment

Nurses expressed that part of the care that provided to resident's families was to ensure that relatives were made as comfortable as possible when spending time in the personal care home setting. This involved the nurse attempting to alter the resident's room to create home-like surroundings. Such behaviours included ensuring that family members had access to comfortable chairs and cots, access to food and coffee, and the use of telephones:

> Jan: "Administration would tell us, well families have to buy their coffee and I'd say no, you know, I mean they can use the coffee pot and they can use coffee from here and, and the end of the day they'd leave

donations, you know, but that captured like the whole, and that resident died so peacefully, you hardly had to give her anything, and with a smile, like, you know, families are just, they just couldn't believe, you know, she died so peaceful. Yes, it was because they were all around and that was very touching."

Wendy: So, I know [the PCH] never used to allow for um, any kind of um, refreshments or whatever for families to be comfortable. And then you have families that are staying and sitting you know for 12 hours and there's nothing, you know, other than having to go outside the building or down to a coffee machine. Now they have a cot, you know, a person can spend the night in the room, um if the cafeteria's open they'll bring coffee and muffins. It's just, it makes it feel more at home. And that's something they never did and I think a lot of families didn't want to leave to go and get a bite to eat because of it. Well I think it was an issue because I know it happened on evenings one time, I called down and asked if I could have something for family members and I know in the daytime you have access to the cafeteria. The family said, 'Well you know, we'll just go to Robin's Donuts and pick up some coffee and donuts.' And I said 'Well, why should you have to?' And basically I called down [to the kitchen] and I said, 'You know, I have family members that have been here most of the afternoon and it's supper time now, do you think I could get some coffee, donuts, whatever, if you have?' And they sent up, and I had said to um, I can't remember the name, it would be nice if this could happen, you know, on a regular basis. It's not like the families don't give to [the PCH]

> all the time that they're there. So to give something to them, a small little thing, you know, it just shows that you're caring about them. Because most people tend not to want to eat."

Part of providing a comfortable environment also involved the nurse attempting to make families feel at home and cared for by the nurse:

> Carrie: "We always ask them if they need anything. We encourage them to stay the night if they, if they so want. We tell them to help themselves to whatever there is, like juice or coffee or tea or food and you know encourage them to call someone to come be with them or encourage them to go home if we see that they've been there constantly."

> Sharon: "They knew what shifts I worked and they would be sure and call, if they were calling for an update. Uh, just how like, he, his mobility, his appetite, his, just a general overview. And then the, when he was dying, we called and uh they both came. And they and they sort of camped out in his room eh. We made them really comfortable, with you know, the most comfortable chairs we could give them. And they just stayed round the clock. So, I don't know it was just giving. I know one of them had a headache but you know how you're not supposed to give, so I gave them some of my Tylenol."

Caring for the Institutional Family

In addition to providing care to dying residents and their families, nurse experts interviewed for this study also indicated that they care for another type of "family" in the personal care home setting: the institutional family. As regards this study, the institutional family refers to fellow personal care home residents and their families and other care home staff. Providing care to the institutional family included i) providing emotional support to members of the health care team, ii) fielding questions from other residents and their families, and iii) providing support to other residents following the death of a fellow resident.

Providing Emotional Support to Members of the Health Care Team

Participants in this study identified that some members of the health care team with whom they worked were uncomfortable in caring for dying residents. To that end, nurses were often in a key position to provide emotional support to such individuals. Supportive behaviours included such things as the nurse providing direction to the health care aides regarding the physical care required to the body immediately following the death of a resident:

> Michelle: "So anyway, when this one did die you know like I went out and I told them that he had passed away and I wanted them to position him and get them off his side so that he doesn't got into rigor mortis like that and you know, if there's teeth, to put the teeth in and to try and hold the jaw up, and anything I said to them they were willing to do you know, so they're very,

> very good. I find that they seem very reverent and very caring and they treat the body well "

Supportive behaviours also included the nurse offering to assist the HCAs in providing care:

> Lori: "Like we have a couple staff members that, are professionals that do not handle death well and, have very difficult time going into the room. And they have a difficult time speaking with the families. Some of the staff don't do well with death. And they avoid the resident. And they avoid the family or um, they don't show the respect for the person. Uh like in um, gossiping back and forth with each other. I would have to say that the staff expect me to be there more."

> Jan: "And yes, I'm involved, when there is a dying resident I go in there all the time, I work with HCA's, um, you know the physical positioning, they don't have the same knowledge of course as an RN. 'Don't be afraid I will do it with you. We'll do it quickly.' But you know, so there is a lot of reassurance on the part of the, um, the HCA's."

Nurses also provided emotional support to other team members following the death of a resident:

> Carrie: "I also, I encourage my staff. I don't know if its silly, and I get kinda. But I encourage them to go say bye."

> Lori: You know, I, I have no problem [dealing with death] and you know [what she'll say to other members of the health care team]: 'let's sit down and cry about this. I'm going to miss him too or uh, you know he's my pet' and you know, you crawl in [the resident's] bed and give them a kiss and a hug."

In providing emotional support to members of the health care team, nurses communicated their belief that there were times when it was appropriate to express their own emotions of sorrow at the bedside when a resident was dying, or had passed away:

> Jan: You know, like, you know walk in a room and the family is there and they cry and then oh, you know, like, you just cry with them. But I feel well that's okay, we're human, we care, you know? We're helping carry a burden."

Fielding Questions from Other Residents and Their Families

Nurses in this study reported that they were often in the difficult position of having to field questions from other residents and their families when a death occurred on the unit. Nurses, being mindful of the grief that some residents may feel, felt that it was important to provide information about a resident's death to other residents:

> Mary: "For the residents too. Because it is important, I mean, it is, they didn't ask where the lady was, but they realized that we had a new resident and they

> know whenever there is a new [sic] is when somebody died. So now, they kind of, who, what….so for her it was um, we felt kind of, I felt bad for them in that way."

> Sharon: "But not, nothing, no sort of, nothing is really acknowledged and they [the other residents] must feel, boy I could go tonight and will anyone even mention my name?"

Such disclosure, however, was hampered by nurses' awareness of concerning disclosure of residents' personal health information to outside parties:

> Anne: "[When a fellow resident dies] you have to be very vague and say 'Well, you know, I can't say what all happened but, he isn't doing as well right now as you can….', or especially if they said 'Well he isn't doing so well, doesn't look so good', you'll say 'Well you know, he, he is, he's got extra needs right now', and you know, you have to be very vague."

> Sharon: "They do [ask what happened to a fellow resident] and then you think with PHIA [Personal Health Information Act], are you allowed to, how much can you say?"

Being vague and not being able to be open and provide other residents with full details regarding the death of a fellow resident had an impact on the nurse in terms of how authentic she was able to feel in her discussions with these other residents:

> Anne: "Which is very difficult but, cause they are very concerned. And some of them know them so well. But you have, and they do understand when you tell them you know you just can't."

Providing Support to Other Residents Following the Death of a Fellow Resident

In addition to fielding questions about the death of a resident in the personal care home, nurses provided support to other residents who they recognized experienced feelings of loss following the death of a fellow resident:

> Anne: "Even the other residents too. They, they grieve. And it's just like they've become a little community and they look after each other. So like the whole unit is, is like a little… and at times, there isn't the same cohesiveness there. Like if you've got more um, recent residents admitted and that. But it doesn't take long and they become a, a little family."

> Sharon: "And they, and they think another one has gone. I know one gentleman saying "You know, a person on either side of me is gone'. So uh, we do put up the obituary on the, on the bulletin board, low enough cause most times the fellas are in wheelchairs. But not, nothing, no sort of, nothing is really acknowledged and they must feel 'Boy I could go tonight and will anyone even mention my name?' And he was in a single room somewhere on another unit in the centre and uh, then he came to us. He had to go into a

> double room, and now he's figured out that in order to get a single room, someone has to die. So he's refused. He said 'I will not take a room that someone has died in, in order for me to get'. So he's staying in his double room. If a, and I know cause one fellow he was in a double room and he wit-, he sort of witnessed two deaths shortly after he was admitted himself."

Consequences of Nurse Behaviours:

Treating Residents and Family with Respect and Dignity

The behaviours that nurses engaged in when caring both for the dying resident, the resident's family members, and the institutional family were designed to create an "atmosphere of caring" in the personal care home setting. When such an atmosphere existed, nurses felt confident that residents, family members and the institutional family were treated with dignity and respect. To the nurses in this study, treating others in this way meant that they were demonstrating that they had defined a personal role for themselves in caring for the dying residents.

> Mary: "I think um, I think respect and dignity from the very beginning. Those people could be my mother, grandmother, grandfather and how I look at this, how, if you know you want your family to be treated in this way, I strive for it for them. So um, I think dignity, the respect. Not because the person dying that you're going to be flippant about a lot of things and talk about your personal stuff over that person. But, you know, maintaining dignity, maintain, give that person what is due that person. I strive for that. I think what they

> need is the respect, the dignity, they need family, they need their families there."

> Michelle: "I find it satisfying to be part of a, part of some end of life. I would love to be in the birthing room and see babies being born, I mean, that's a time of joy. And this is the opposite end of life, there's not often too much joy associated with it. So you're just there to be able to help this person leave this world with dignity and to also help the family to get into the initial stages of losing."

The way that nurses demonstrated respect for dying residents was to provide care the way that the nurse would care for members of her own family:

> Wendy: "More times I think at [the PCH] we just have um, people that just seem to think that we treat the residents as if they are our own. And a lot of times, yes we do. And you get that um, closeness with family members so that they know you and you know them and it's an easier process to deal with in the long run."

> Anne: "So you do develop a real rapport and they become like your, you know Grandpa or your [chuckle]…. they become part of a family. And um they feel that way about you as well. Like you know they're like 'how are you doing, how was your weekend?' You know they'll do the same thing as you would to them."

Likewise, nurses also approached the resident's family and the institutional family as if they were their own:

> Mary: "I know nurses have this tendency to think the family's in the way, you know they get that the family's in the way. I don't look at it like that the families in the way; I look at it like, who else would you want there when you're pretty sick if not your family? When you're sick for yourself? I often tell my staff, this is my way of thinking....look at it as though it's your family, treat them the way you would like to be treated or your family to be treated."

> Lori: "We're more in tune with the family than we are the resident. We're, we're so used to um, we are their family and we're, we're as close to the family as we are to the resident. You have to get in there with them like they're your own."

Summary

This chapter has presented the characteristics of the sample that participated in the study, and delineated the 9 critical nurse behaviours identified by nurse experts regarding caring for dying elderly residents in a personal care home setting. Chapter Six will present a discussion of the findings in view of past research and relevant extant literature, and outline the implications of the study for nursing education, practice and research.

CHAPTER SIX

DISCUSSION

Introduction

This chapter will provide a discussion of the findings that emerged from this study as they relate to the overall purpose of the project, the theoretical perspective guiding the study, the relevant literature, and the proposed research questions. Limitations of the study will also be presented. The chapter concludes with a discussion of the implications of the study for nursing education, practice and research.

Critical Nurse Behaviours in the Care of Dying Elderly Residents

The overarching aim of this study was to describe the behaviours that nurse experts identify as critical to the care of dying elderly residents in the personal care home setting. The majority of the nurses who participated in this study indicated that they were surprised to have been nominated by their colleagues because they felt that in providing end of life care to dying residents, they didn't do anything extraordinary compared to other nurses or personal care home staff. These feelings may be explained by the fact that nurses accrue clinical knowledge over time and are often unaware of their clinical achievements (Benner, 1984). Nurses in this study were able to easily recall specific details and circumstances about death events involving former personal care home residents. Although most considered themselves to be members of the nursing unit's health care team and attributed successes to the team rather to themselves, some of the participants recognized their own unique qualities that enhanced their ability to care for dying residents. More importantly, nurses were able to identify when their interventions made a difference in the care of the dying resident and could articulate what those interventions were. While the sample of nurses per facility was small, it should be noted that there were no notable differences regarding critical nurse behaviours identified by the study participants employed at each of the two facilities utilized in this study.

The findings from this study regarding critical nurse behaviours resulted in the generation of three main conceptual categories: i) care of the dying resident; ii) care of the dying resident's family; and iii) care of the institutional family. These conceptual categories, and the sub-categories and behaviours associated with them will now be discussed within the context of extant literature.

Care of the Dying Resident

Care of the dying resident emerged from the findings as a major category containing three sub-categories of critical nurse behaviours: i) promoting the provision of psychosocial care and ii) co-ordinating symptom management efforts. A discussion of these behaviours will be presented next.

Promoting The Provision Of Psychosocial Care

Promoting the provision of psychosocial care emerged in this study as a sub-category of behaviours directed at caring for the dying resident. The findings of this study, with regard to critical nurse behaviours directed toward the dying resident, are very much in keeping with the work of Mcilfatrick and Curran (2000) who attempted to provide the distinction between the "doing" of end of life nursing care and the "being" a real presence for the dying patient and their family. These researchers reported the findings of a study to examine district nurses' perceptions of palliative care services within the community setting. A questionnaire which focused on the key areas of defining palliative care, perception of roles, communication, service provision and the educational and training needs of district nurses was completed by nurses (n = 66) in two communities in Northern Ireland. They stated that aspects of care associated with symptom management and maintaining quality of life are better understood within the traditional context of doing, while the other aspects of care, such as promoting independence and providing psychological care and support could be considered as being with the patient. These authors also suggested that the doing-for aspect of the nurse's role not be underestimated or undervalued, because in the provision of such care the nurse is also providing emotional support and care for both the patient and family. These findings from the literature resonate with the findings of the current study.

A significant nursing behaviour directed at promoting the provision of psychosocial care included ensuring a physical presence at the resident's bedside so that the resident did not die alone. Behaviours to this end included the nurse attempting to get the family into the personal care home before the resident died, and if this was not possible, delegating another individual to the resident's bedside. Sometimes the nurse herself provided the bedside presence to the dying resident. The importance of providing a presence has been identified in the literature. Katz (2003) reported the findings of a large multi-faceted study that she and colleagues conducted to ascertain if the principles and practices of palliative care had been incorporated in residential and nursing homes, and to assess the feasibility of applying appropriate aspects of palliative care to the care of people dying in these settings. Interviews conducted with managers (n=100) as part of that study revealed that 25% of the homes had a policy mandating that residents should not die alone. This is in keeping with work of Nolan, Featherston and Nolan (2003), who conducted a large-scale convenience sample survey of caregivers (n = 367) in New Zealand to suggest ways in which a more holistic approach to death and dying could be promoted in care homes in the United Kingdom. The researchers reported that particular efforts were made by caregivers providing care to dying residents in care homes to ensure that residents did not die alone (Nolan et al., 2003).

Research also suggests that family members value being able to be present at the bedside of a dying elderly relative. As part of their larger study examining death and dying in long-term care, Wilson and Daley (1999) explored family perspectives on dying in this setting. Qualitative interviews with 11 family members from 11 long-term facilities from the mid-western United States who had experienced the loss of the resident within the previous four weeks of the study were conducted. Family members identified that participation in the dying process was important to them – specifically with respect to being present at the time of the resident's death. Wilson (2001) concluded that every effort should be made to notify families early enough that they may be present at the time of the resident's death, if that is their wish.

Previous research examining expert nursing behaviours in care of the dying has also identified importance of ensuring the presence of family members at the time of the patient's death. Degner and colleagues' (1991) qualitative study examining care of the dying adult on the palliative care unit described nurses maintaining involvement with, and a presence for the family while the patient was imminently dying in terms of "responding during the death scene". Maintaining a presence was coupled with the provision of spiritual comfort in Harbeck's (1995) examination of critical nurse behaviours in care for the dying on adult medical units. In that study, "being present" was described in the context of the nurse both being physically present in the patient's room as well as establishing a trusting relationship with the patient that communicated that the nurse saw a person rather than a disease.

As regards the provision of psychosocial care, the nurse experts in this study identified that they advocated on the resident's behalf to shield the resident from being caught up in the stressful dynamics of difficult or dysfunctional family relationships. This finding did not emerge from the previous research investigating critical nurse behaviours in care of the dying (Degner et al., 1991; Harbeck, 1995; Hawkins, 1995; Helwer, 1994; McClement & Degner, 1995). This may be explained because involvement of family appears to be a larger factor in the provision of nursing care in the personal care home setting than in other settings. Moreover, nurses have the opportunity in the personal care home setting to develop long-standing relationships with residents and their families, compared to acute care settings. For these reasons, nurses may be more aware of difficult relationships between family members. Strained family relationships were not identified in the literature as a barrier to the provision of quality end of life care in the personal care home setting, except in the context of differences in family's expectations regarding a resident's health outcome, or disagreement about the appropriateness of various therapies and courses of action to take with respect to care of the dying resident (Ouimet-Perrin, 2004).

The literature discusses three profiles of family adaptation in the face of a relative's terminal illness: i) the highly adaptive family, ii) the less adaptive family, and iii) the midrange adaptive family (Ferszt and Houck, 1986). The authors describe highly adaptive families as able to express feelings of grief, yet also maintain a sense of hopefulness. The authors also stated that because these families can realistically identify their own needs, work together to solve problems, make use of resources, and operate on a high level of trust, the nurse is able to establish a good working relationship with them quickly and often find them gratifying to work with.

Ferszt and Houck (1986) describe the less adaptive family as being at the other end of the continuum. These types of families do not express their feelings directly and it is therefore difficult to determine what the family members are saying or feeling. The authors stated that personal anxiety levels are high in these types of families, which prevents the members from perceiving the needs of others. As a result of their own needs having frequently gone unmet, it is difficult for individual family members to acknowledge and support one another (Ferszt & Houock, 1986). The authors reported that when nurses encounter the less adaptive family, an accepting and non judgemental attitude will be difficult for the nurse to maintain, which will result in the nurse emotionally abandoning these families or becoming caught in the middle of their intense dynamic processes.

The third type of family is the midrange family that exhibits a mixture of the characteristics described previously in the other two extremes. Communication patterns in this type of family are not as clear and direct as in the highly adaptive families, nor are they as confusing as in the less adaptive ones (Ferszt & Houck, 1986). The authors caution the nurses to avoid siding with one member or another, or becoming the spokesperson for any particular individuals, or getting caught in the middle between conflicting factions, which is not easy to avoid.

In the current study, nurses acknowledged that while stressful relationships exist in families, they felt that a dying resident shouldn't have to bear witness to tense encounters between family members who are at odds with one another. Nurses thought that family members should put their differences aside and present as a "united" unit to the dying resident so that he/ she could "go in peace". Nurses also expressed that they felt frustrated and "caught in the middle" when families were in conflict because they could not assist family members to support one another in the face of the resident's impending death. Nurses therefore engaged in behaviours to try to get family members to be considerate of the dying resident's needs and would encourage families to put the conflict aside for the benefit of the resident.

While the concept of advocacy is often cited in the nursing literature as something that nurses should do, the ways in which a nurse acts to advocate on his/ her patients' behalf are not well described. Ouimet Perrin (1997) defined "patient advocacy" as the ability to form a human connection with the patient and to assist that patient to determine the direction of his/ her care. While this attempt to clarify the concept of advocacy was commendable, the definition failed to describe the specific behaviours that nurses engage in when they "connect" with their patients in the process of advocating for them. Baldwin (2003) completed a concept analysis to clarify what she described as the "ill-defined concept of patient advocacy." Results of her analysis revealed that advocacy has three defining attributes: i) a therapeutic nurse-patient relationship in which to secure patients' freedom and self-determination, ii) promoting and protecting patients' rights to be involved in decision-making and informed consent, and iii) acting as an intermediary between patients and their families or significant others, and between them and healthcare providers (Baldwin, 2003). The author summarized these attributes as valuing, apprising, and interceding and stated that inherent in each is the nurse who is proactive as well as reactive (Baldwin, 2003).

Coordinating Symptom Management Efforts

Coordinating symptom management efforts was the second major theme that emerged from the findings regarding care of the dying resident. Such care involved the nurse engaging in behaviours that reduced the physical suffering of residents, and included nursing assessments, ensuring the provision of appropriate care to alleviate distressing symptoms, and advocating on the resident's behalf. Previous research examining expert nurse behaviours in care of the dying has also identified that providing comfort was an important nurse behaviour (Degner et al., 1991; Harbeck, 1995; Hawkins, 1995; Helwer, 1994; McClement & Degner, 1995). These studies identified that nurses engaged in behaviours that improved physical comfort (Degner et al., 1991), reduced physical and psychological pain (McClement, 1993), reduced physical pain and satisfied psychological and emotional needs (Hawkins, 1995;

Helwer, 1994) and reduced or eliminated physical pain, and prevented unnecessary procedures including resuscitation (Harbeck, 1995).

The findings from this study indicate that nurses in the personal care home setting rely to a great extent on health care attendants to provide both the majority of the direct care to residents, and to report changes in a resident's condition. An important part of coordinating the symptom management efforts in the personal care home thus also included the nurse educating other members of the health care team about what changes in status to attend to, and what they might mean. This finding has been reported by Hanson et al. (2002) in their study with nursing home staff and physicians conducted to define a good death in a nursing home and to describe factors that promote or prevent good care for the dying in this setting. The researchers found that certified nursing assistants in the personal care home relied on nurses for clear explanations about changes in a resident's health status.

Receipt of information indicative of a change in a resident's status served as the impetus for nurses to engage in the nursing process to more fully assess the resident to determine the extent of the distress being experienced. Assessment data were then used to devise a plan of care, and then evaluate the outcome of that care. The importance of the nursing assessment, particularly as it relates to the personal care home environment is supported in the literature. Rose (1995), in a discussion article exploring the role and knowledge needs of all nurses with terminally ill patients, focused on the significance of the nurse's contribution in assisting patients and families to deal with both physical and psychosocial problems. The author emphasized the importance of the nurse's careful physical and psychosocial assessments of each dying patient (Rose, 1995). Rose (1995) stated that nurses have a potentially extensive and complex role in the care of terminally ill patients and families because nurses frequently care for patients over a prolonged period of time and are therefore in a position to observe and monitor the incidence and severity of symptoms and the efficacy of treatment. Ersek et al. (2000), in their study examining the educational needs and concerns of licensed nursing staff and certified nursing assistances regarding end of life care, also emphasized the importance of the nurse's role in appraising the effectiveness of the treatments implemented for the management of end of life symptoms, stating that assessment of symptoms is the first step to managing these problems. The researchers stated that pain and symptom management are the hallmark of end of life care (Ersek et al., 2000).

Following assessment of the dying resident, the nurse was responsible to determine the next course of action. Sometimes, this involved the nurse providing care to alleviate the distressing symptom by administrating medication or contacting the physician. These actions are in keeping with the "doing for" behaviours outlined in the literature review section of this thesis (p. 66). While the term "doing for" was coined by Davies and Oberle (1990) to describe the nurse's focus on the physical care of a patient, other authors have identified specific nursing behaviours and responsibilities that comprise the doing-for role of the nurse in the provision of care to dying patients. For example, the importance of the nurse's "doing-for" role was emphasized by Rose (1995) in her discussion article aimed at exploring the role of the nurse working with terminally ill patients. The nurse's role in assisting the patient to achieve physical comfort vis-a-vis nursing management of physical symptoms such as pain, nausea and vomiting, was highlighted. Gauthier's (1998) discussion article regarding the role of the palliative care nurse in managing patients who experience suffering at the end of life, stressed the nurse's responsibility to ensure that appropriate medication and dosages are prescribed and that they are properly administered. Hall et al. (2002), in describing the findings of a chart audit of the last 48 hours of residents lives life in residents in long-term care, reported that nurses were often the primary care providers, following standing orders left by the physicians. The researchers also emphasized the crucial roles for nursing staff who work with dying residents in vigilant care to ensure good symptom management, support to families of the terminally ill, communication with other health team members and objective documentation.

In the current study, long-standing relationships with residents and families were described as being extremely important in ensuring the delivery of quality end of life care. That is, nurses' knowledge of the resident, and their desires regarding interventions in the context of end of life care figured prominently in shaping the symptom control strategies that were implemented and the overall care plan that was crafted. Ersek and Wilson (2003) have suggested that the length of a resident's stay in a personal care home improves the staff's abilities to individualize the care provided to a particular resident. Furthermore, close relationships allowed staff to detect subtle clues that occurred during the course of terminal illness, and long-term daily contact also promoted knowledge and understanding regarding residents' values, personal goals and care preferences. Participants in this study indicated that these by-products of close relationships identified in the literature were particularly beneficial when a resident's condition had deteriorated to the point where they could not express themselves any longer, and thus were unable to make their wishes known.

In coordinating symptom management efforts in the personal care home, the nurse also engaged in behaviours that involved advocating on the resident's behalf. In the current study, in addition to nurses advocating on a resident's behalf as previously discussed with respect to promoting the provision of psychosocial care, nurses also advocate for residents in coordinating symptom management efforts by ensuring that the resident's wishes regarding end of life care were known and that the health care team abided by those expressed wishes. Previous research examining critical nurse behaviours in the care of the dying captured the notion of patient advocacy to a smaller extent in other care setting with nurses engaging in behaviours that "help patients do things that are important to them" in the palliative care unit (Degner et al., 1991) and the pediatric hospital setting (Hawkins, 1995). Helwer (1994) in her study of in the community included behaviours that demonstrate the nurse's confidence in advocating and decision-making.

The reason that resident advocacy emerged so strongly from the findings in the current study of the personal care home environment might be attributed to the close relationships that develop between personal care home staff and residents over time. According to Ersek and Wilson (2003), such relationships promote knowledge and understanding regarding residents' values, personal goals and care preferences. According to the American Nurses Association (1996), it is the responsibility of the nurse to facilitate informed decision making for the patient at the end of life. Ouimet-Perrin (2004) stated this responsibility begins when the nurse encourages an elderly patient to consider what would be important to him or her at the end of life, continues with the nurse educating the patient about end of life care options and is completed when the nurse advocates for and delivers the type of care the older adult desires at the end of his or her life.

An important part of the advocacy role in the coordinating of symptom management efforts involved nurses endeavoring to avoid unnecessary hospitalization of the dying resident. While it has been reported that between 67% and 90% of residents (Hanson, 2003; MCHP, 2004; Reynolds et al., 2002) will remain in the personal care setting until death, many of these individuals nearing the end of life are transferred to hospital, including a terminal hospitalization for some. Bottrell et al. (2001) studied the perceptions of Directors of Nursing regarding the transfer decision–making process and institutional structures for appropriate decision-making regarding transfer of dying nursing home residents to the hospital versus keeping those residents in the home until death. The findings from that study revealed that nurses play a substantial role in personal care home-to-hospital transfer decisions. The researchers reported that the Directors of Nursing believed that nurses are the key mediators for transfers as a result of their 24-hour presence with residents.

In the current study, nurses questioned the necessity of transferring some dying residents to hospital. The necessity of such transfers has been questioned in the literature as well. Kayser-Jones, Weiner and Barbaccia (1989) reported a portion of the findings of a larger study that investigated the social-cultural factors and other circumstances influencing the decision-making process in the evaluation and treatment of acute illnesses in nursing homes. The study used participant observation;

in-depth interviews with physicians, nursing staff, personal care home residents and family members (100 in each category) and event analysis to gather data. The researchers claimed that 48.2% of resident transfers from personal care home to hospital were due to social-structural (i.e., lack of support services, nursing/ medical issues such as an insufficient number of adequately trained nursing staff and poor nurse-physician communication, and family pressure for transfer) rather than for clinical reasons, and thus could have been avoided.

The findings of this current study investigating critical nurse behaviours in the care of the dying elderly resident also suggests, however, that expert nurses also recognize that on occasion, the transfer of a dying resident is warranted. Participants indicated that sometimes they had no choice but to transfer the resident to hospital if this is what the resident had specified when they made decisions about their care, or if family insisted on the transfer. Travis et al. (2002) stated that family members often either will not or cannot choose to forgo aggressive curative care, such as hospitalization or tube feedings for an older relative, because they want to limit the likelihood that they may later feel regret that they withheld potentially effective treatment. Participants in this study indicated that sometimes it wasn't until hospital staff determined and communicated to the resident and family that the resident was in the terminal state that family were able to realize and understand the medical condition of the resident. This observation is consistent with the findings of Travis et al. (2002) who stated that it may take a hospital admission for the care home staff, resident, and family members to understand, recognize, and agree that the resident is truly in the terminal phase of life. In addition, hospitalization may be the clinician's only option in response to a resident's terminal decline, if advance care planning was not or could not be addressed with the resident or family prior to the need for hospital care (Travis et al., 2002).

Personal care home nurses in the current study supported the belief that residents should remain in their own homes surrounded by their family and those close to them, and expressed that unnecessary transfer of a dying resident to the hospital was a significant burden on the resident. It should be noted however, that in situations where a resident had made their desires to go to hospital known in advance, the resident's wishes took precedence, despite this decision being against the nurse's better judgment.

Sidell and Komaromy (2003) reporting on findings from their large-scale study investigating the quality of care provided for those dying in residential and personal care homes in England, examined the extent to which home managers, care staff and general practitioners understood and operationalized palliative care concepts in practice. Study findings indicated that all categories of personal care home staff shared understandings of what constituted a "good death." The researchers found that when a resident was determined to be possibly dying but was experiencing a medical condition that was possibly treatable, then arguments could be put forward for transferring them to a hospital where such treatment was available. The authors also stated that when a resident was determined to be dying and not treatable, then there was a strong argument for keeping them in the facility because it was considered to be their home and the place where they felt most comfortable.

According to Hanson, Henderson & Menon (2002) who used focus groups with nursing home staff and physicians to define a good death in a nursing home and describe factors that promote or prevent good care for the dying in this setting, the decision to transfer a resident to hospital is further complicated by the slow trajectory toward death often seen in the personal care home setting and punctuated by acute and apparently reversible illnesses such as pneumonia, sepsis and dehydration. Furthermore, episodes of acute illness could occur repeatedly prior to death, which meant that determining the right course of action became more difficult for the nurse (Hanson et al., 2002).

In addition to advocating to protect the resident from the burdens of what nurses perceived to be futile treatment or unnecessary transfer to hospital, the findings of this current study suggest that nurses also advocated on the resident's behalf to ensure that changes in medical status were not brushed off and therefore not addressed because of the perceptions of physicians that these changes were just related to the resident's age. According to Matzo and Witt Sherman (2001), the conventional wisdom is that because a person is of advanced age, symptoms normally amenable to palliative care are seen to be commensurate with normal consequences of aging. This perception creates the potential for health care providers to overlook or minimize an elderly person's complaints of physical discomfort, if the resident in fact reports the discomfort. Matzo and Witt Sherman (2001) also stated that many elderly patients erroneously consider some symptoms, such as pain weakness or fatigue, to be inevitable signs of aging, not problems to be treated. Rose (1995), in her discussion article aimed at exploring the role of the nurse working with terminally ill patients emphasized the nurse's role in assisting the patient to achieve physical comfort vis-a-vis nursing management of physical symptoms such as pain, nausea and vomiting. To this end, nurses engage in behaviours to ensure that symptoms are assessed and treated (Gauthier, 1998). Furthermore, while Gillick and Mendes (1996) state that most elders have a strong tendency to favour limitation of treatment when they are unlikely to return to their baseline functioning or are probably dying, Ouimet Perrin (2004) contends that this is not always true and that some elders wish to continue to live until specific events occur or goals are reached. Ouimet Perrin states that when the nurse engages in discussions with elderly patients regarding advance care planning and end of life decision making, the nurse has the opportunity to learn what the elder and family believe will probably be important as the end of life approaches and can advocate on the resident's behalf.

In the literature, staffing issues and a lack of available time to spend with residents were presented as major barriers to the provision of quality palliative care in the personal care home setting. Parker and De Bellis (1999) reported that nurses experienced guilt and stress in looking after residents who were dying, particularly because of their inability to sit and just "be with" the dying resident when he/ she had no family. The authors also indicated that nursing staff consistently identified a lack of time to provide the quality of care they wanted to give to residents and their families. Ersek et al. (2000) indicated that this lack of time to provide quality care to dying residents was often cited as a major source of stress for nurses and certified nursing assistants in personal care homes. Wilson and Daley (1998) stated that staff believed that residents should not die alone, yet it was often not possible to be with a dying resident. Despite the negative impact of workload on the ability of nurses to provide psychosocial care identified in the literature, expert nurses in this study did not identify workload issues as particularly constraining their ability to provide end of life care.

While participants acknowledged the nurses' reliance on other health care team members, namely health care attendants, to deliver the majority of the direct care to dying residents in the coordinating of symptom management efforts, participants indicated that when a resident was dying, the nurse's priority became the resident and their family. As such, the nurse would become more involved in the delivery of the care to that resident.

With respect to symptom management, lack of a physician's presence in the personal care home was also identified in the literature as a barrier in the provision of palliative care (Gibbs, 1995; Wilson & Daley, 1998; Wilson 2001). Hanson et al. (2002), who conducted a study involving nursing home staff and physicians defining what constituted a good death in a nursing home and describing factors that promote or prevent good care of the dying in this setting, reported that although physicians were rarely physically present in the personal care home facility, they still remained responsible for medical treatment orders. The researchers also reported that physicians acknowledge their unwillingness to spend more time in personal care homes and their need to rely on the nurses' assessment skills and communication in their provision of medical care to residents in this setting. Interestingly, despite the lack of a physician's presence in the personal care home setting, (a reality for nurses interviewed for this study), participants did not identify this as impacting the end of life care that they provided. This may be because nurses did not know when and why they might have required a physician's involvement because the nurses were unsure of when a resident was actually dying. The literature has reported that the dying trajectory of older people who had chronic health concerns is often characterized by a lack of certainty (Field and James, 1993), largely because of the absence of a significant event (such as blood chemistry results, or an obvious and pronounced decrease in activity tolerance) signalling that the illness had entered its terminal phase (Komaromy et al., 2000). Furthermore, the identification and assessment of symptoms at the end of life in an elderly resident is difficult for several reasons. First, it is not uncommon for the primary health care provider to care for a dying older adult who does not report symptoms of weakness, fatigue, pain, or anorexia simply because many older patients erroneously consider these symptoms to be inevitable signs of aging, and not as problems to be treated (Matzo & Witt Sherman, 2001). Second, many residents experience a significant degree of cognitive impairment in the personal care home. This has implications regarding the extent to which residents are able to make verbal reports of their symptoms (Hall et al., 2002). Third, there is a vast amount of literature citing the need for improved end of life care nursing education, particularly for personal care home nurses (Ersek et al., 2000), suggesting that these nurses may not have the knowledge to be able to assess symptoms adequately. One other reason for participants not identifying lack of a physician's presence as constraining their ability to provide optimal end of life care is that in the nurse's everyday practice with residents who are dying and those who are not, the presence of a physician is lacking in the personal care home. Therefore, physician absence may have been accepted by participants in this study as "just the way it is" and was therefore not judged as being particularly problematic when caring for a dying resident. For all of these reasons, nurses may not be able to identify the need for physician involvement for the purpose of symptom management with some residents who are dying.

Care of the Resident's Family

Consistent with the findings in this study, past research examining critical nurse behaviours in care of the dying have identified the theme of caring for the family (Degner et al., 1991; Harbeck, 1995; Hawkins, 1995; Helwer, 1994; McClement & Degner, 1995). "Responding to the family" as it was designated in the previous research, emerged from all of these studies as a specific category of nursing behaviours with respect to the family. Responding to the family in the previous studies included behaviours that: 1. responded to the family's need for information; and 2. reduced the potential for future regret. Authors of the previous studies also identified additional behaviours under the "responding to the family" category which were specific to the findings of each individual care setting examined: Behaviours that included family in the patient's care or relieved them of this responsibility according to what was best for the family (Degner et al., 1991; Harbeck, 1995; Hawkins, 1995); behaviours that support the whole family, behaviours that bring families together, behaviours that foster a home-like environment and behaviours that support the child/ family's cultural and religious beliefs and practices (Hawkins, 1995); behaviours that connect and support the family and its members and behaviours that prepare the family for the death event (Harbeck, 1995); behaviours that facilitate the transition from cure to palliation (McClement & Degner, 1995); and behaviours that provide emotional support to the family (Helwer, 1994). Additional categories of behaviours made reference to some specific nursing behaviours directed at family members and care outlined in Table 1.

Unlike previous studies wherein the majority of nurse behaviours were directed toward the dying patient, this study demonstrated that the majority of categories of nurse behaviours were directed toward the dying resident's family members. Personal care home nurses were very much involved in providing care to the resident's family and this may explain the emergence of a major category of critical nurse behaviours that were with respect to the dying resident's family.

What accounts for nurses directing so much care to the family in the personal care home setting? First, the connections between nurses and families often developed over a period of time and were not limited to the time frame during which the resident was actively dying. Hanson et al. (2002) contended that the opportunity for longitudinal relationships is a unique asset of nursing home care, impossible in hospital or hospice with short lengths of stay. The continuity of caring relationships between residents and personal care home staff may be a compelling strength of this setting (Hanson, 2003). The findings of this research suggest that these more enduring relationships enable nurses to better anticipate families' needs and plan for their care when the resident was dying. This is consistent with the literature reporting that a good relationship with visiting family enables the personal care home staff to better support the family through the difficult period of a resident's terminal illness.

Established levels of familiarity appear to make it easier for staff to be able to provide families with support at such times of vulnerability (Komaromy, 2003).

Second, Wilson & Daley (1999) contend that the family role in the personal care home may be intensified when a resident is dying because family members are feeling a great deal of stress. While Swigart (2004) acknowledged that family members caring for ill or dying elderly patients in the nursing home or hospital setting experience the burdens of caregiving, such as role conflict, guilt, depressive symptoms, anxiety, stress and fatigue (Forbes, Bern-Klug & Gessert, 2000), there is some evidence suggesting that the stress experienced by families in personal care home settings is different than in other settings. Forbes et al. (2000) studied family caregiver end of life decision making for personal care home residents with dementia. Family caregivers described making end of life decisions in the context of overwhelming burden and underlying guilt related to placing the relative in the personal care home. Given these additional burdens on families who are already experiencing the distress associated with the impending loss of a loved one, personal care home nurses recognize the family members' needs for support during this difficult time and attempt to devote the time and energy that is required to provide care to families in order to alleviate some of their suffering. Lastly, the findings of the current study suggested that from the nurse's perspective, the direct care of the family is almost more essential to the nurse, while the needs of the dying resident are attended to by other personal care home health care team members. The importance of the nursing needs of the family may be attributed to the fact that the palliative care needs of family members when the resident is dying are generally in the realm of supportive, psychosocial care. Such care, particularly in the final days and hours of the resident's life, are most meaningfully directed toward the family. The literature supports the position that that nurses must be prepared to provide this type of nursing care in delivering end of life care (Wilson & Daley, 1999; Davies and Oberle, 1990; CHPCA, 2002). According to Swigart (2004), the provision of palliative care to the family is important in the immediate clinical moment, and in the future of the family unit. Swigart (2004) stated that family members' experiences associated with the dying and death of a close relative can produce negative and lasting disturbances in health; or, in contrast, the experiences can become part of the personal growth and contribute to the family legacy.

Four critical nurse behaviours emerged from the study specific to care of the family including: i) providing a presence/ respecting the need for privacy; ii) breaking bad news; iii) educating family members/facilitating decision-making; and iv) providing a comfortable environment.

Providing a Presence/ Respecting the Need for Privacy

Providing a presence, while respecting the family's need for privacy emerged as one of the critical nurse behaviours directed towards the family when the resident was dying. Participants in this study talked about the importance of nursing behaviours that ensure that the family does not feel abandoned. Behaviours to this end included providing both a physical presence for the family when the resident was dying, while at the same time, being cognizant of the family's need for privacy at this highly emotional time. Nurses appreciated the fact that some families may want to express final sentiments to the dying resident and say “good bye” in private. For those family members, it was important that the nurse respected that need while also ensuring that they still felt as though the nurse was available to them should they have questions or require some support.

The provision of a presence, while respecting the need for privacy, was also identified in the previous research examining critical nurse behaviours in the care of the dying in other clinical settings (Degner et al., 1991; Harbeck, 1995; Hawkins, 1995; Helwer, 1994; McClement & Degner, 1995). These nursing behaviours were identified in previous works within the rubric of ways of being supportive to family members. Wilson and Daley’s (1999) research examining what families identify as helpful in coping with the loss of a relative in a long-term care setting identified that it was important that staff took the time to come into the resident’s room to see if the family needed anything and to assess how they were doing. These authors also reported that families appreciated that staff respected their privacy and seemed to know when they wanted to be left alone.

Breaking Bad News

The second critical nurse behaviour that emerged from the findings of this study with respect to the care of the dying resident’s family was the breaking of bad news. Study participants identified the importance of being able to break bad news to family members in an effective and timely manner. “Bad news” in the context of this study refers to the worsening of a resident’s condition or the death of a resident. This behaviour was not identified in the previous works investigating nurse behaviours in care of the dying (Degner et al., 1991; Harbeck, 1995; Hawkins, 1995; Helwer, 1994; McClement & Degner, 1995). This may be explained by virtue of the lack of a physician's presence in the personal care home setting compared to acute care settings. Whether or not the responsibility of breaking bad news just defaulted to nurses in the personal care home because physicians were rarely physically present, nurses in this study did not express concern over it being their responsibility. This may be because they feel it is appropriate for them to convey such news to families, given the long-standing nature of the relationships that they have with families.

In the oncology and palliative care literature, "communicating bad news" is often associated with receiving news of a terminal diagnosis. There is, however, some published research with respect to the personal care home setting and the communicating of bad news in this care context. Komaromy (2003) reported on the findings of a study that she and colleagues conducted to explore the needs of relatives and other residents when a death occurred in the personal care home setting. In that study communicating news of a resident's death to family members was identified as being largely the role of the home's manager. The authors stated that it was unclear whether this was a formally recognized process or a practice that established itself over time. However, care staff interviewed for the study indicated that informing relatives of the death was something that they disliked doing and thought that it was a task that senior staff were paid to do. In the current study however, participants indicated that breaking bad news was mainly the responsibility of the registered nurse on the personal care home nursing unit and that not being able to communicate bad news in a sensitive and effective manner could result in negative feelings on the part of the family. The importance of the nurse having the capacity to show empathy in her dialogue with family members has been identified in the literature (Bohnet, 1986). A theoretical writing by Bohnet (1986) also stated that if the nurse demonstrates a genuine interest in the family member to whom they are speaking, the nurse is showing empathy emotionally and physically. Given the vast amount of literature that describes the close relationships between personal care home staff and the families of residents, it only seems appropriate that the personal care home nurse be the one to communicate bad news to a resident's family.

Participants in this study indicated that approaches to delivering the bad news were dependent upon the route by which the communication was going to take place. Communication could take place either in a conversation over the telephone, or in-person in the personal care home facility. When delivering the information to family members via telephone, nurses began by alerting the family member that bad news was about to be delivered. This type of approach is consistent with one of the ways Levetown (2001) suggests nurses approach the process of breaking bad news. She stated that nurses should provide a "warning shot" or an introductory sentence before presenting the distressing information (Levetown, 2001). Conversely, when delivering bad news to family members in person, the findings of this study suggest that personal care home nurses do not provide the warning shot as previously described. Rather, the nurse appears to get to the point quickly. This difference in nursing approach to delivering distressing information may be explained by the fact that the nurse is able to engage in face-to-face interaction when delivering bad news in-person, and therefore has the opportunity to observe non-verbal cues and to show empathy in conversation with the family member. Observing non-verbal cues and showing empathy are components of therapeutic communication (Du Pen & Robison, 2001).

Educating Family Members/ Facilitating Decision-Making

The third critical nurse behaviour that emerged from the findings concerning care of the family was that of educating family members. Participants stated that personal care home nurses need to provide information and explanations to families about what to expect regarding anticipated changes in the resident's health status in the face of physical deterioration, and to provide details surrounding the death event itself. This is consistent with the previous research that concluded that the nurse must respond to the family's need for information (Degner et al., 1991; Harbeck, 1995; Hawkins, 1995; Helwer, 1994; McClement & Degner, 1995). Wilson and Daley (1999) studied family perspectives on dying in long-term care settings and found that family members described several caring behaviours of staff that were important to them when their loved on was dying. In particular, family members identified that participation in the dying process was important. Participation in the dying process in that study included understanding the dying process (Wilson & Daley, 1999). Therefore, Wilson (2001) stated that it is important for families to understand the dying process, and that personal care home staff explain signs and symptoms of approaching death to families to keep them informed of what is changing and why.

In educating family members, the personal care home nurse also provides guidance to the family in the decisions they are required to make. For example, when residents are unable to express their own wishes regarding care, families were often involved in decisions about which medical treatments/ procedures were to be provided, and whether or not to transfer the resident to acute care facility. This is consistent with Wurzbach's (2002) observation that in the personal care home setting, families need to depend on nurses to provide guidance regarding treatment decisions.

The findings of the current research suggest that there are three strategies personal care home nurses employ to guide family members in the decision-making process. First, participants in this study indicated that they assisted families by outlining the options available in a given situation. For example, nurses explained to family members the ways that particular changes in the resident's health status, such as decreased oral intake in the dying resident, could be managed. According to Wurzbach (2002), education for the family is essential in making end of life treatment decisions, and the author stated that families depend on nurses to provide knowledge and guidance, which not only provide information but also support. Wilson (2001) also stated that nurses provide support to families by way of open communication with families regarding changes in the resident's condition and answering family members questions honestly.

Second, the nurse assisted the family to weigh the potential benefits of a particular choice against the potential burden on the dying resident. For example, the nurse would explain the pros and cons of transferring the resident to hospital. According to Carter and Chichin (2003), residents and loved ones need reassurances that not transferring a resident to hospital does not preclude solid medical and nursing care, including pain and symptom management. Bottrel et al. (2001) stated that nurses play a substantial role in nursing home-to-hospital transfer decision-making and that increasing nurses' understanding of the philosophy and goals of palliative care at end of life may increase/ improve nurses' abilities to talk about option in end of life care with families.

Third, participants indicated that it was important for nurses to assist families to clearly delineate what the resident's expressed wishes to be regarding the selection of treatment options in situations where the resident could not make these expressed wishes known. This strategy has been identified by Quill and McCann (2003) as being an effective approach to reduce family members' feeling solely responsible for decisions regarding patient care. This "substituted judgement" involves getting persons closest to the patient to try to represent the patient by making decisions as they believe the patient would (Quill & McCann, 2003). Mitty and Mezey (2004) described substituted judgement as calling on a surrogate person's knowledge of the patient's wishes, preferences, values and principles, and if possible, his or her past decision making to facilitate the decision maker to infer how the patient would evaluate the benefits and burdens of a treatment him- or herself.

All of the strategies employed by the nurse to guide families in their decision-making were employed with the intent that families would reach thoughtful, informed, decisions in order to reduce the potential for future regret. Travis et al. (2002) stated that family members often either will not or cannot choose to forgo aggressive curative care, such as hospitalization or tube feedings for an older relative, because they want to limit the likelihood that they may later feel regret that they withheld potentially effective treatment.

Nursing behaviours that reduce the potential for future regret were also identified in the previous research conducted in the area of nurse behaviours in the care of the dying and with respect to responding to the family (Degner et al., 1991; Harbeck, 1995; Hawkins, 1995; McClement & Degner, 1995). It should be noted however, that in other clinical settings, the ways that nurses reduced the potential for future regret were different when compared with the current study. For example, Degner et al. (1991) suggested that activities that promoted quality of life for the dying patient usually had a benefit for the family, and therefore nurses would involve the family in the personal care of the patient. Other researchers discussed additional ways that nurses could reduce the potential for future regret, some of which were specific to a particular clinical setting and included such behaviours as: initiating discussion about death and dying with family (Hawkins, 1995); encouraging families to be present at the death scene; helping families identify if these was something that needed to be said or done before the patient died (Harbeck, 1995); ensuring that families have liberal access to the patient, and broaching the subject of organ donation (McClement & Degner, 1995). In the current study examining the personal care home setting, it appears that the main factor affecting family members' potential for regret concernd the issue of surrogate decision-making, which is consistent with the literature (Quill & McCann, 2003; Wurzbach, 2002). The findings of this study suggest that nurses may be able to reduce the potential for feelings of future regret by family members in their communication and information sharing with family members and guiding families in decision-making.

Fostering a Home-Like Environment

Another nurse behaviour that emerged from the findings and was directed at family members was fostering a home-like environment. One previous researcher (Hawkins, 1995) identified this behaviour as important in her study investigating nurse behaviours when the dying patient was a child in a hospital setting. This behaviour may not have emerged in research examining expert nurse behaviours in care of the dying on acute medical units (Harbeck) and intensive care settings (McClement & Degner, 1995) as nurses are limited as to the types of home-style modifications they can make in such settings. Degner and colleagues did not identify the behaviour in the palliative care settings, perhaps because there is already attention given to creating a home-like atmosphere on the unit, and such modifications were a non-issue. According to Kayser-Jones et al. (2003), although there has been limited research about the physical environment in settings where people are dying, it is a significant factor that must be considered. The authors stated that privacy and space are necessary so that residents can have time with their families and bring closure to their lives, and that a noisy environment detracts from the respect and dignity that residents and their families want and deserve (Kayser-Jones et al., 2003).

While the personal care home served as the resident's place of residence, it was also a clinical setting where individuals receive nursing and medical care. Flexibility in personal care home facilities allowed nurses in the current study to "customize" the care provided to residents and families by attempting to create a physical setting that was comforting, home-like and familiar to the individual dying resident and their family. According to Wilson (2001), the environment of the personal care home should promote resident autonomy and quality of life. Also, as part of providing a comfortable environment, nurses were able to provide family members with the comforts of home such as refreshments, use of telephone and a comfortable place to sit. In this way, rather than altering the physical setting, nurses attempted to make families feel more at home within the personal care home unit. This is consistent with the findings of research conducted by Wilson & Daley (1999) who studied family perspectives on dying in long-term care settings. These authors reported that family members appreciated caring activities from the staff such as bringing them coffee or providing them with a comfortable chair. It appears that the fostering a home-like environment is both perceived by nurses as an important behaviour in caring for the family of a dying resident in the personal care home and received and appreciated by families as an illustration that nurses do care for and about families.

Care of the Institutional Family

The last category of nurse behaviours that study participants discussed as being important in the care of the dying resident in the personal care home setting included responding to the care needs of the institutional family when a resident dies. As regards this study, the institutional family refers to fellow personal care home residents and their families and other care home staff. Providing care to the institutional family included i) providing emotional support to members of the health care team, ii) fielding questions from other residents and their families, and iii) providing support to other residents following the death of a fellow resident. The nurse behaviour of caring for the institutional family did not emerge from the findings of previous research regarding expert nurse behaviours in care of the dying (Degner et al., 1991; Hawkins, 1995; Helwer, 1994; McClement & Degner, 1995). Harbeck (1995) included behaviours that demonstrate responding to other patients under the category of responding after death has occurred. This may be because the notion of the institutional family is unique to this care environment by virtue of the fact that the personal care home is both a clinical setting as well as a home environment, and the long-standing relationships that develop between members of the institutional family.

Providing Emotional Support to Members of the Health Care Team

Participants in this study identified that some members of the health care team with whom they worked were uncomfortable in caring for dying residents. To that end, nurses were often in a key position to provide emotional support to such individuals charged with the responsibility of providing such care. Other studies that investigated critical behaviours in the care of the dying also recognized this important role that nurses have and categorized these types of behaviours as "responding to colleagues" (Degner et al., 1991; Harbeck, 1995; Hawkins, 1995; Helwer, 1994; McClement & Degner, 1995). Such nursing behaviours included those that provide emotional support and critical feedback to colleagues. Furthermore, the findings of this current research suggest that personal care home nurses too grieve the loss of a resident who has died. This is not surprising given the close relationships that develop between residents and nurses as has been identified both in this study as well as in the literature. In fact, Hanson and Henderson (2000) stated that the intensity of the relationships that carers have with residents resembles that of families and therefore they may require bereavement support in the same way as family members do.

Members of the health care team may also need support because of the need to continue to provide care while simultaneously having to deal with the death of a resident on the unit. Komaromy (2003) has described the tension of staff needing to be able to care for living and dying residents in the same setting and even simultaneously on the same shifts. She also stated that they have to cope with the grief reactions of all those concerned, including their own, following the death of a nursing home resident. Findings from the current research suggest that personal care home nurses find it difficult to have to provide emotional support to residents and staff when they themselves are also in need of such support following the death of a resident. Nurses indicated that it was difficult to "switch gears" quickly to admit a new resident into the personal care home following the death of a resident and reported that there is little available by way of emotional support to other residents and staff. This is consistent with the literature reporting that while there is the recognition that personal care home staff require emotional support, personal care home administrators are often unaware of the intensity of staff feelings toward residents (Wilson, 2001).

Despite the intense emotional burden of loss experienced by participants in the study by Ersek at al. (2000) assessing the educational needs and concerns of nursing home staff regarding end of life care, participants noted the paucity of opportunities for self-care and for attending to their own grief. Comments from participants in that study suggested that nursing home staff frequently suppress their feelings about loss, in part because they are unable to express their emotion while at work (Ersek et al., 2000). Ersek at al. (2000) reported that emotional attachment and multiple losses have a toll on staff and that administrators should develop strategies to allow for the expression and support of emotional attachment to residents and guidance in self-care techniques. According to Vachon (2001) grief can accumulate over the years and lead to significant depression. She suggested that self-care and support strategies can decrease burnout and help maintain a high level of patient care (Vachon, 1998). This reality underscores the need for these facilities need to develop programs to assist staff in coping with the loss of a resident (Wilson, 2001).

Fielding Questions from Other Residents and Their Families

Nurses in this study reported that they were often in the difficult position of having to field questions from other residents and their families, when a death occurred on the unit. According to Wilson and Daley (1999) personal care facilities are home for many people, and residents come to consider other residents and family members as surrogate family. In the literature regarding the personal care home setting, the institutional family is receiving increasing attention. Participants in this study indicated that other residents and their families need to be advised of the death of a fellow resident and that the nurse must be prepared to answer questions regarding the death. Komaromy (2003) stated that the news of a death needed to be given in a way that took into account the perceived needs of other residents which included as assumed concern about their own demise.

Providing Support to Other Residents Following the Death of a Fellow Resident

In addition to fielding questions about the death of a resident in the personal care home, nurses had to be prepared to provide support to other residents who they recognize experience feelings of loss following the death of a fellow resident. According to Wilson (2001), the loss of a resident may be stressful for other nursing home residents. Nurses indicated that residents grieve the loss of a fellow resident with whom they may have established a close relationship with over time, may have shared a room with or sat beside at meal times. Wilson (2001) stated that the death may remind residents of their own mortality. This is consistent with the findings from the current study.

In the other studies investigating critical nurse behaviours in the care of the dying, Harbeck (1995) identified that the nurse's "responding after the death has occurred" included behaviours that demonstrated responding to other patients who were still alive. The researcher described how nurses on medical wards supported other patients on the unit by acknowledging the death event and responding to their particular needs for support (Harbeck, 1995).

Consequences of Nursing Behaviours

The findings of the current study suggest that one overarching theme encapsulated the nursing behaviours that nurses described as being important in the care of the dying elderly resident in the personal care home setting: treating the dying resident, their family and the institutional family with respect and dignity. Participants identified that there was a mutual closeness between residents and families, and that above all, nurses identified that they strived to engage in behaviours that demonstrated respect and dignity. To this end, nurses described behaviours that were indicative of the nurse having defined a personal role in caring for dying residents and their families. This is in keeping with previous research regarding nurse behaviours in the care of the dying (Degner et al., 1991; Harbeck, 1995; Hawkins, 1995; Helwer, 1994; McClement & Degner, 1995). The behaviour that emerged from the current study as critical to accomplishing this was to treat dying residents and family members as nurses would their own families. In the literature, health care provider-patient relationships were deemed critically important when providing care to people who were dying (Kayser-Jones, 2002). In fact, some authors contended that the term "family" could describe all those living and working within the personal care home (Froggatt et al., 2000; Carter & Chichin, 2003). Wilson and Daley (1998) stated that attachment was fostered by staff's efforts to care for residents and in some cases be their "family". Hanson (2003) stated that the best nursing home nurses and nursing assistants became like a family and that their relationships provided comfort during the dying experience.

In the provision of end of life care, a fundamental principle is that the patient and family together comprise the unit of care (Chekryn-Reimer & Davies, 1991; Ley, 1989). Thus, caring for the family indirectly equated to providing care to the resident and vice versa. This emerged from the findings as a behaviour having a positive influence in the care of the dying. Providing comfort and support to the dying resident has a reciprocal and often lasting effect on the family (Swigart, 2004). Family members' experiences associated with the dying and death of a close relative were identified as producing negative and lasting disturbances in health, or in contrast, the experiences could become part of personal growth and contribute to family legacy (Swigart, 2004). It was for these reasons that critical nurse behaviours identified in this study were directed at treating both the dying resident and their family with respect and dignity.

Study Findings as Regards the Proposed Research Questions

The findings of the current study, revealed that nurses participating in this study were readily able to identify behaviours having a positive influence on the care the dying elderly resident in the personal care home setting (Research Question #1). However, study participants struggled when asked to identify behaviours that had a negative influence on care of the dying resident (Research Question #2). Only one nurse expert identified a situation she believed exemplified a negative care approach. This nurse expert relayed the details of an encounter between a registered nurse, and a dying resident's family. The registered nurse, whose first language was not English, was seen as being ineffective in breaking bad news to members of the family regarding the resident's decline in health status. The nurse expert explained how the family was visibly distraught by what appeared to be the nurse colleague's harsh approach in relaying the upsetting information to the family. This exemplar in turn, lent support to the critical nurse behaviour regarding breaking bad news as regards care of the dying resident's family as identified in the current study.

The nurses' inability to identify negative examples in this study is consistent with the findings of some of the previous authors who studied critical nurse behaviours in the care of the dying in the adult medical unit, pediatrics and the community/ home care (Harbeck, 1995; Hawkins, 1995; Helwer, 1994). These researchers reported that while participants in their studies identified some negative care behaviours, they appeared to have less difficulty identifying positive behaviours as compared negative ones. Several factors may account for this. Helwer (1994), whose research involved the identification of expert nursing behaviours in care of the dying in the community postulated that the nurses in her study may have felt ill at ease in describing areas of their own practice that were less than optimal. The desire to appear competent in provision of end of life care of the dying resident may also explain why nurses in this study were unable to identify negative care behaviours. The inability to identify negative care behaviours they have witnessed other nurses engage in may stem from a reluctance to want to criticize a fellow colleague. Moreover, given the solo nature of the nurses' practice in the personal care home setting, participants in this study simply may not have had a repertoire of experiences in working with other nurses upon which to draw.

The findings of the current study show that participants identified three factors facilitating their ability to provide optimal end of life care to the dying elderly resident in the personal care home (Research Question #3): i) the ability to establish close, long-standing relationships with residents and their families, ii) the existence of the "institutional" family, and iii) the availability of reliable members of the personal care home health care team (namely health care attendants) to assist in the provision of skilled end of life care. These findings are in keeping with the extant literature that supports personal care homes as appropriate places for the provision of palliative care for dying elderly residents because of the emotional attachment that tends to develop between residents and their long-term care providers. Furthermore, it was reported by Hanson (2002) that a length of a resident's stay in a personal care home improves the staff's abilities to individualize the care provided to a particular resident. Hanson et al. (2002) stated that the opportunity for longitudinal relationships is a unique asset of nursing home care. The literature supports that residents spend considerable time in personal care home settings prior to their death, during which attachment to health care providers may occur. Moreover, although nursing home staff acknowledged that close bonds with residents caused them to grieve after each death, they valued the highly individualized care they were able to provide as an essential in good care for dying residents (Hanson et al., 2002). This is consistent with the information reported by participants in the current study. Residents may also become attached to others who also live in the personal care home setting. Wilson and Daley (1999) observed that personal care facilities are home for many people, and residents come to consider other residents and family members as a surrogate family. In fact, the term "family" could describe all those living and working within the personal care home (Froggatt et al., 2000). Also consistent with the published literature regarding the provision of end of life care to dying residents, participants reported that they rely to a great extent on health care attendants to provide both the majority of the direct care to residents, and to report changes in a resident's condition. According to Hanson and Henderson (2000), health care attendants have a significant role in the provision of quality patient care in the personal care home setting because they are often the first to observe the subtle changes in behaviour, mood or intake that characterize terminal decline.

As regards Research Question #4, participants identified four factors constraining their ability to provide optimal end of life care in the personal care home. Such factors included: i) failure of the facility to provide supportive, home-like environment to the dying resident's family; ii) dealing with difficult and/ or dysfunctional family dynamics; iii) hospitalization of the dying resident; and iv) the lack of facility administrative support to the institutional family following the death of a resident. Participants in this study reported they attempted to make families feel more at home within the personal care home unit by providing family members with the comforts of home such as refreshments, use of telephone and a comfortable place to sit. However, because they reported that administration did not always support the idea of facility resources being utilized by those other than residents, nurses identified that they had to make families feel at home without facility administration being aware that they were doing so.

In the current study, nurses acknowledged that while stressful relationships exist in families, they felt frustrated and "caught in the middle" when families were in conflict because they could not assist family members to support one another in the face of the resident's impending death. This was identified as a significant factor constraining their abilities to provide optimal end of life care to the dying resident. In situations involving difficult family relationships, nurses reported that they had to engage in behaviours to try to get family members to set their conflicts aside and be considerate of the dying resident's needs.

While participants in the current study reported that some transfers to hospital could not be avoided, the unnecessary transfer of a dying resident constrained the nurse's ability to provide quality end of life care. The findings suggested that nurses did not believe that resident should be moved into unfamiliar surroundings, under the care of unfamiliar caregivers when the outcome would be that the acute care setting had nothing to offer that resident in terms of curative interventions.

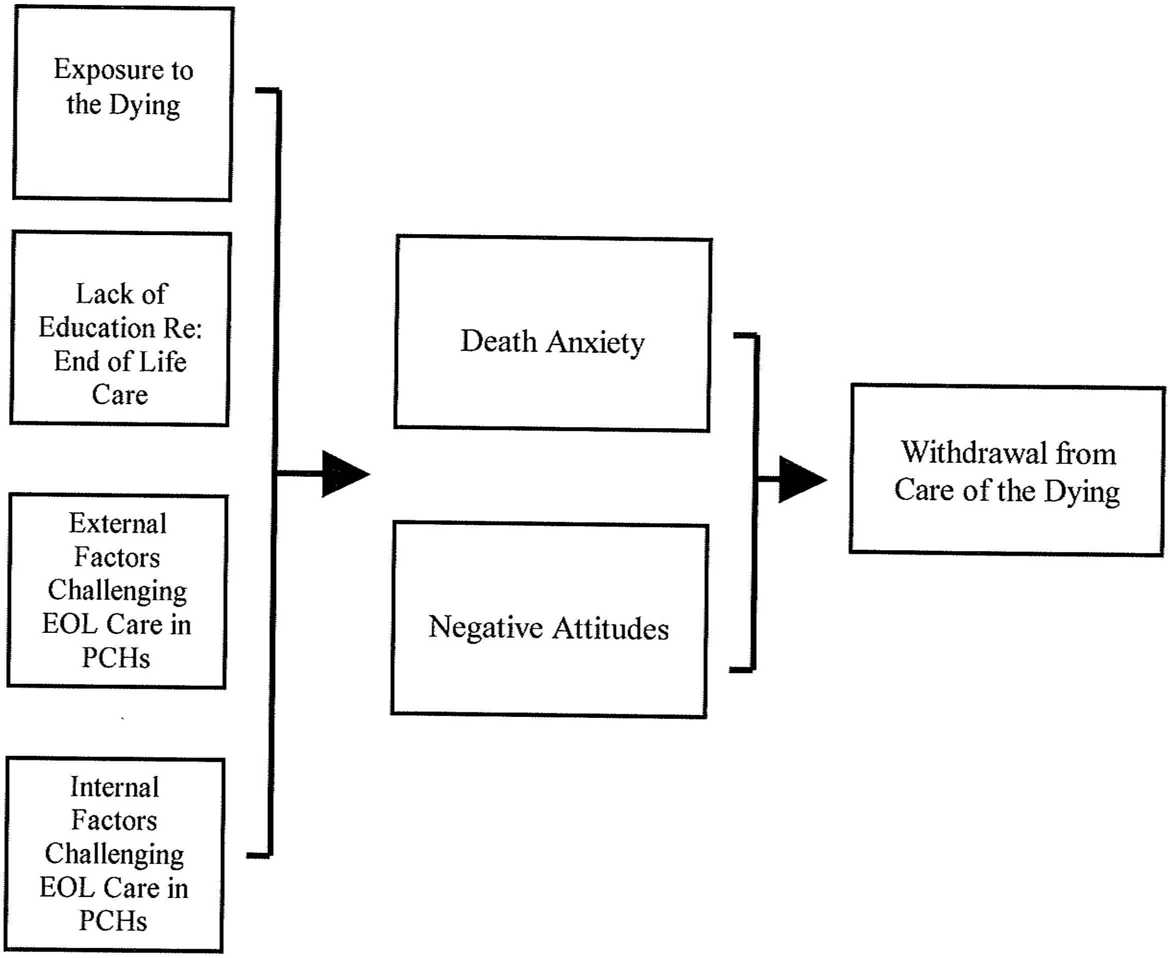
Finally, nurses reported that a lack of support to the institutional family from the facility's administration following the death of a resident constrained their abilities to provide optimal end of life care. The findings of this study suggest that personal care home nurses grieve the loss of a resident who has died. This is not surprising given the close relationships that develop between residents and nurses. Hanson and Henderson (2000) stated that the intensity of the relationships that carers have with residents resembles that of families and therefore care providers may require bereavement support in the same way as family members do. Nurses in the current study indicated that it was difficult to "switch gears" quickly to admit a new resident into the personal care home following the death of a resident and reported that there is little available by way of emotional support to other residents and staff. Therefore, members of the health care team are also in need of support, particularly as they continue to provide care to surviving residents while simultaneously having to deal with deaths that occur on the unit. While the general literature regarding the provision of end of life care identifies that members of the health care team will require emotional support, personal care home administrators however, may not recognize the extent of this need in this setting, as they are often unaware of the intensity of staff feelings toward residents (Wilson, 2001). Ersek at al. (2000) reported that emotional attachment and multiple losses have a toll on personal care home staff and that administrators should develop strategies to allow for the expression and support of emotional attachment to residents and guidance in self-care techniques.

Nurses in the current study recognized that other residents experience feelings of loss following the death of a fellow resident and indicated that they had to be prepared to provide support to surviving residents. Nurses indicated that residents grieve the loss of a fellow resident with whom they may have established a close relationship with over time, may have shared a room with or sat beside at meal times. Nurses reported that there was a lack of support available within the personal care home setting to adequately address the needs of surviving residents, as well as other members of the institutional family, following a death on the unit.

Discussion Regarding Quint's Model in Light of Study Findings

Quint's (1967) theoretical perspective and model of nursing care of the dying was the sensitising framework that was used to guide this study. Quint proposed that the lack of exposure of nursing students to dying individuals coupled with a lack of education about end of life care fostered death anxiety, negative attitudes and a nurse's subsequent withdrawal from dying patients. A review of the literature regarding care of the dying resident in a personal care home setting revealed that various internal and external factors operate that present additional challenges to nurses in the provision of end of life care in this setting. Please refer below to the replica of the revised conceptual framework below (Figure 2) as it was introduced in Chapter Three.

Figure 2. Revised Theoretical Model:



An important factor influencing nurses' experiences in care of the dying resident emerging from this study that has not been identified in the literature concerns the solitary nature of registered nursing practice in the personal care home setting. All participants in this study commented that they were often the only registered nurse on the nursing unit in the personal care home in which they worked, caring for between 20 to 40 residents at a time. The nature of nursing care provided by registered nurses in the personal care home setting included: overseeing the care provided by all disciplines on the unit; administration of medications; nursing assessments and the provision of medical treatment procedures (such as wound care and urinary care); communicating with physicians and obtaining medical orders; contacting pharmacy and ordering medications; arranging medical appointments for residents; arranging transfers of residents to and from appointments/ hospital; and consulting other disciplines as required. Participants acknowledged that while a registered nurse functioned alone on evening and night shifts, when working the day shift on a 40-bed nursing unit they were often paired up with another nurse to provide the required nursing care. The registered nurse's partner however, was rarely another RN. In fact, the RN was usually partnered with a Licensed Practical Nurse (LPN). Under such circumstances, the RN was responsible for all of the nursing care delivered on the unit, including that provided by the LPN. This meant that the RN was required to oversee the care provided by the LPN while also having to provide direct nursing care to a designated number of residents. The findings from this study clearly underscore the largely "solo" nature of the work that nurses do in the personal care home setting.

There is a lack of literature describing the nature of the work of registered nurses in personal care homes. Leppa (2004) attempted to redress this gap by conducting a pilot study to explore the nature of nursing work in long-term care nursing home environments and comparing it to the nature of nursing work in the intensive care unit environment. The researcher reported that participants emphasized the complexity of the medical and psychosocial needs of their patients and identified the psychosocial needs of the patients' family members and how dealing with these needs is an unrecognized and often extremely time consuming aspect of long-term care nursing work. Leppa (2004) concluded that the long-term care nursing work environment is a complex, demanding and interesting one that is different from, not less than, nursing work in intensive care units. This researcher's work is admirable in that it challenges the assumptions that nursing in long-term care nursing homes is less intellectually challenging, less physically demanding, and less skilled work than nursing in acute care environments (Leppa, 2004). However, the researcher compared her findings, based on the responses from registered nurses and licensed practical nurses, to data about intensive care unit nursing that came from a study 15 years prior and involved registered nurses only. While Leppa (2004) mentioned the role of long-term care nurses in working with a variety of professional and unlicensed staff members, the registered nurse practicing in isolation from other registered nurse colleagues did not emerge from the findings of her study. This is likely because the sample for her study included registered nurses and licensed practical nurses.

Kayser-Jones et al. (1989) studied factors contributing to the hospitalization of nursing home residents and discussed the burdens on nurses working in personal care homes in terms of being the only registered nurse on the unit and having to provide care to a number of heavy care patients in addition to supervising the care provided to a large number of other residents. While the authors described this as "an impossible task!" (p. 507), these findings were discussed as concerning as they related to the shortage of nursing staff in this setting and the resulting tendency to transfer dying residents to the hospital unnecessarily when the resident's condition deteriorated.

Because registered nurses function in relative isolation from colleagues with equal or greater health educational preparation, they do not have the opportunity either to observe end of life care that is delivered by their peers, or receive peer-feedback regarding their own performance regarding care of the dying resident. Research conducted by Degner and colleagues (1991) identified that in the provision of end of life care, nurses relied on their colleagues to provide constructive criticism, as well as positive feedback when some aspect of the care was particularly well done. Such feedback constitutes an important part of the nurses learning about how to deliver optimal end of life care. The absence of such feedback has implications for the way that nurses learn about themselves and the way that they provide end of life care. Given the independent nature of the nurse's work and the lack of formal and informal support systems (namely registered nurse colleagues) in the personal care home setting, nurses who work in this setting may experience heightened death anxiety in the discharge of their duties. This in turn has the potential to impact on the quality of end of life care that they will be able to provide.

In addition to the solitary nature of nurses work in the personal care home setting, and the limited opportunities to receive peer feedback that this engenders, the literature suggests that nurses working in personal care homes typically do not receive the same opportunities for end of life care education compared to nurses working in more acute care settings (Ersek et al., 2000). Given the health care system's cure-orientation, Ersek et al. (1999) health care providers are typically poorly educated about care of the dying. Not surprisingly, nurses have described their professional education as being less than adequate in preparing them for providing care to a dying patient (Kristjanson & Balneaves, 1995; Redman, White, Ryan & Hennrikus, 1995). It is therefore unclear as to where and the extent to which a personal care home nurse obtains knowledge about the provision of end of life care. It appears that nurses in the personal care home setting are forced to learn about the provision of end of life through independent learning, (if this is a practice that they choose to engage in), and the process of trial-and-error in their experiences with dying residents. This is concerning for two reasons. First, with respect to independent learning, Ferrell, Virani and Grant (1999) stated that nurse cannot practice what they do not know, and that basic knowledge is contingent upon accurate, current and comprehensive information provided through textbooks. An evaluation of the palliative care content in nursing texts however, revealed many deficiencies – palliative care represented 2% of the total content in nursing textbooks (Ferrell et al., 1999). Ferrell et al. (1999) stated that the texts also contained inaccurate information and a lack of information regarding critical palliative care topics.

Second, the independent nature of the personal care home nurse's work, and her reliance on personal experience as a means of learning about end of life care, is concerning. Benner (2001) stated that the person with limited background knowledge will lack the tools needed to learn from experience. Thus, the personal care home nurse is at a disadvantage in terms of educational preparation for the delivery of end of life care. This combination of lack of educational opportunities, in conjunction with the absence of peer feedback, is troublesome.

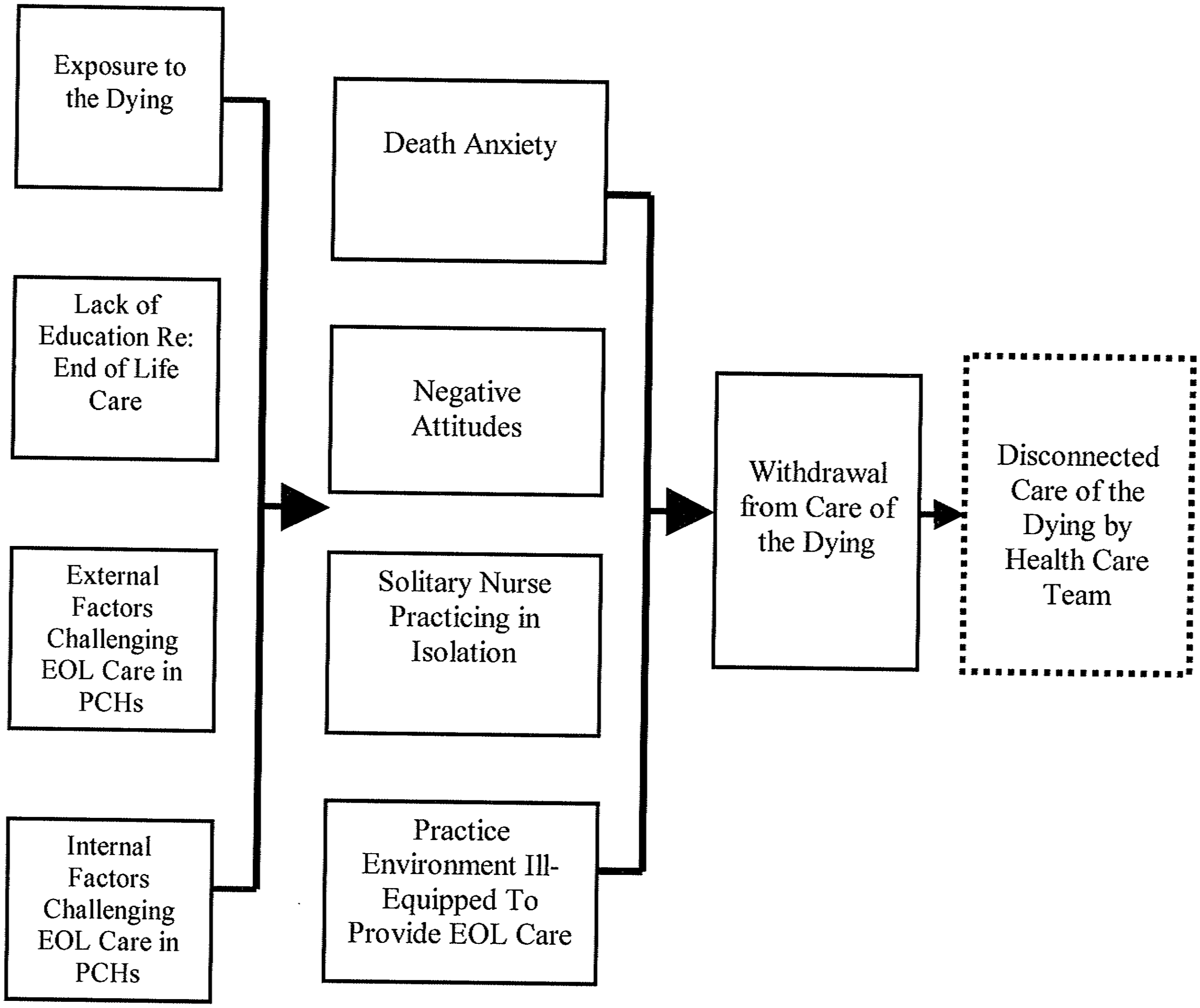
Critical nurse behaviours that involve the provision of emotional support and critical feedback to colleagues, coined " responding to colleagues" emerged in a series of previous studies investigating critical nurse behaviours in the care of the dying on the palliative care unit (Degner et al. 1991); medical unit (Harbeck, 1995); patients with cancer in the community (Helwer, 1994); pediatric medical unit (Hawkins, 1995) and adult intensive care unit (McClement & Degner, 1995). The absence of its identification in the study of personal care home nurse behaviours thus is of significance. According to Arnold and Egan (2004), working with dying patients can trigger a nurse's awareness of personal loss and fears about his or her own death and mortality. Death anxiety occurs when the nurse is confronted with fears about death and has few resources or support systems to explore thoughts and emotions about dying and death (Vachon, 2001). Participants in this study identified that following the death of a resident, a lack of formal support mechanisms exist to provide emotional support to them. Furthermore, participants reported that they had no time to process the death before having to admit a new resident into the deceased resident's former room. According to Vachon (2001), nurses often experience difficulty dealing with their feelings of grief and loss at the time of death because of other responsibilities that must be attended to immediately. Furthermore, a lack of support from colleagues can have a negative impact on the nurse's ability to provide ongoing end of life care. The development of supportive, collaborative work relationships may be fundamental to enhancement of self-efficacy and self-esteem (Vachon, 2001). While Vachon (2001) reported that this is especially important for those nurses working alone in the community, this can be supposed as the case for personal care home nurses as well as they also work in isolation. If a nurse is unable to process the deaths of former patients through appropriate grief and personal death awareness, he or she may begin to distance himself or herself from emotional involvement with the patient and family (Egan & Labyak, 2001). Egan and Labyak (2001) state that this may negatively affect not only the coping ability of the nurse but also the quality of compassionate delivery of care and the ability to meet the needs of dying patients and their families during the terminal phases of an illness.

The extant literature on the provision of end of life care in personal care homes contends that this particular environment may not be conducive to the provision of this type of care. Travis, Loving, McClanahan and Bernard (2001) asserted that neither the term "palliative care" nor the associated approaches to such care have been well integrated into most personal care home facilities. In fact, they stated that the barriers to fully implementing high-quality, comprehensive palliation in this setting are better documented in the literature than are reports of successful end-of-life programs (Travis et al., 2001). The number and types of the barriers that affect each individual personal care home facility also factor into the quality and type of end of life care that nurses in personal care homes will be able to provide.

Proposed Revisions to Quint's Theoretical Model

Quint proposed that exposure to dying individuals coupled with a lack of education about end of life care fostered death anxiety, negative attitudes and a nurse's subsequent withdrawal from dying patients. The uniqueness of the personal care home care context, the number and types of factors posing challenges to nurses in the delivery of end of life care, along with the findings of this research, suggest that Quint's theoretical model serves as an effective guide. Quint proposed that a nurse's exposure to dying individuals along with a lack of education regarding the provision of end of life care, may lead to negative attitudes and death anxiety. A review of the literature has identified numerous barriers (external and internal factors) challenging the implementation of palliative care in the palliative care setting. These factors lead to circumstances where the registered nurse is practicing in relative isolation from registered nurse colleagues in a setting that may be ill-equipped to support the provision of quality end of life care. As a result, and as Quint (1967) suggests, a lack of positive experience in care of the dying can decrease the likelihood of a personal care home nurse's personal involvement with dying residents to the extent that he/ she withdraws from the dying resident. The findings of this research identified the leadership role of the registered nurse in the provision of end of life care. The nurse functions as the point person for the health care team and is therefore becomes a driving force behind the end of life care that a dying resident receives. Given this significant role for the registered nurse in the personal care home in the provision of end of life care, this researcher suggests that Quint's model be further modified to reflect how the nurse's attitude towards a dying resident may set the tone for the care provided by the health care team in this setting. In other words, a nurse who withdraws from caring for a dying resident may result in the resident receiving disconnected care from the health care team overall. A modified version of Quint's model is therefore proposed and is depicted below in Figure 5:

Figure 5. Modified Theoretical Model:



Limitations of the Study

The following limitations were placed upon the study:

1. The Sample –Only two personal care home facilities were represented and all participants were female. Drawing a sample from a larger population of nurses who represent a larger number of facilities would ensure that the findings of the research are reflective of the nurses' perceived role and subsequent critical nurse behaviours in the care of the dying in a personal care home. In terms of the sample of participants, it would desirable for the sample population to be more reflective of the actual population of nurses who provide care in personal care home with regard to the percentage of male nurses in this setting (6.3% in Winnipeg).
2. Data were collected in face-to-face interviews and the interviewer's verbal and non-verbal reactions to the experiences participants recounted had the potential to influence the tone of the interaction. By introducing a component of participant observation into future research would afford the researcher the opportunity shadow the nurse experts and observe what they do in care of the dying to determine whether it is consistent with what they say they do and would help to minimize the reliance on the interviews as the sole means for obtaining data.
3. The researcher's previous experience in the personal care home setting and current experience in the provision of end of life care may have influenced the results of this study. Although the intention was to remain objective, inherent biases and expectations about nursing behaviours may have been present. This

is because the interviewer may have unknowingly and unintentionally looked for specific nursing behaviours to emerge from the findings given the researcher's biased view of the importance of the nurse's role in delivery of end of life care in the personal care home environment. While the effects of researcher bias was minimized in the current study through the process of member-checking, such bias may be further minimized in future research by incorporating use of a collaborative approach in conducting the study, particularly with respect to the analyzing the data.

Implications of the Research

The findings of this study investigating critical nurse behaviours in the care of the dying elderly resident in the personal care home provide the foundation upon which recommendations for education, practice, future research and personal care home administration can be developed. Recommendations stemming from the current research will be presented next.

Recommendations for Education

1. Basic nursing education programs must include a compulsory palliative care course. The extant literature affirms that current basic education programs for nurses do not adequately prepare nurses for the delivery of end of life care (Degner & Gow, 1988; Irvine, 1993). Nurses have also indicated as much. Improved nursing education regarding the provision of care to dying persons and their families will help to better prepare nurses for the delivery of this

important care in all clinical settings, with improved quality of care to patients and families being the ultimate end result.

2. Palliative care nursing education courses must include topics that are relevant to all terminal illnesses and medical conditions where patients will require end of life care. The extant literature regarding the profile of personal care home residents suggests that dying elderly persons do not fit the mould of patients typically requiring palliative care services as they were originally intended. This is also important as the philosophy of "palliative care" is incorporated into clinical settings that were not previously identified or acknowledged as a designated provider of end of life care, such as the personal care home.
3. Palliative nursing education must incorporate the findings of empirical research, such as the current study and previous research that investigated critical nurse behaviours in the care of the dying, into their programs. This would ensure that nursing education reflects the range of care behaviours that nurses engage in across the many clinical settings where end of life care is delivered, and would also serve to emphasize the specific nurse behaviours that nurses identified as being important in particular care environments.
4. Personal care homes must be acknowledged as settings for the provision of end of life care and as such, the needs of the elderly vis-a-vis end of life care and the unique role of the nurse in the provision of end of life care in this setting must be incorporated into basic palliative care education courses. Thus, the personal care home setting must be included as a viable option for student placement for practical nursing experiences in palliative care.

5. Personal care home staff must become the targets for specialized continuing education regarding the provision of end of life care. This would help to increase their levels of knowledge and comfort in the delivery of such care, and would better prepare them for their encounters with difficult family members and dysfunctional families.

Recommendations for Practice

1. Nurses must acknowledge the importance of supporting one another (informally or otherwise), and other health care team members, in the face of practicing in isolation and experiencing repeated loss.
2. Critical nurse behaviours in the care of dying elderly residents in the personal care home identified in this study could serve as the basis for criteria that nurses who practice in this setting could be evaluated upon. As such, these behaviours could be incorporated into performance appraisal documents to serve as established goals for nurses' practice.

Recommendations for Research

1. The close relationships that develop between personal care home staff and residents and their families currently touted as so important at end of life and a hallmark of the care provided in personal care homes may be altered given the changing profile of residents being admitted to these settings. Research will be required to investigate changes in personal care home residents' needs in face of these changes.

2. In the current study, there appeared to be an emphasis on nursing behaviours directed at addressing the care needs of the family, versus the nursing care required by the dying resident. More research is required to explore these findings that emerged with respect to nurses' role in the provision of care to the dying resident's family as this information would then have to be incorporated into the educational preparation of nurses who will deliver care in the personal care home setting.
3. Research exploring personal care home residents' and families and other members of the health care team's views of critical nurse behaviours in the care of the dying elderly resident in this setting would assist to further describe the crucial role of registered nurses in the personal care home in the provision of end of life care. This would help to identify the expectations that health care team members have with respect to other team members and would help to determine whether overall care behaviours of the personal care home health care team are congruent with the needs of dying residents in this setting so as to minimize the disconnectedness in the care delivered to dying residents.

Recommendations for Administration

1. Personal care home programs and administrators need to demonstrate their commitment to the provision of optimal end of life care through the revision of mission statements to include the principles of quality end of life care, and

pledging to participate in facilitating the revisions to quality indicators for personal care home facilities.

2. Regional health authorities must acknowledge the personal care home as a setting that will increasingly be providing end of life care and as such, must endeavour to support these facilities financially to ensure that subsequent needs for improved resources will be met, such as improved staffing levels.
3. Administrators must collaborate with staff to develop a consistent process, in keeping with confidentiality laws for the protection of personal health information, for the notification of the institutional family (personal care home staff and other residents) regarding the death of a resident.
4. Administrators must acknowledge the emotional support needs of the institutional family following the death of resident and in collaboration with staff and resident representatives, such as the resident council, regarding how to meet the identified needs.

Summary

This study attempted to redress the gap that currently exists regarding the nature of expert nursing practice in care of the dying resident in a personal care home setting. Interviews with 10 nurse experts led to the identification and description of 10 critical nurse behaviours in the provision of end of life care to elderly residents of personal care homes. According to Benner (1984), the systematic documentation of expert clinical practice is a first step in clinical knowledge development as it allows new areas of clinical knowledge to be identified for further study and development.

Identification of such behaviours can be used to provide the basis for a model of expert care of the dying elderly in personal care homes, and help to build upon previous research aimed at identifying expert nursing practice in care of the dying. The identification of the specific care-giving behaviours the nurse can engage in may also help to decrease a nurse's feelings of inadequacy, reduce the risk of the nurse withdrawing from the dying patient, thereby enhancing quality care of the dying, and promote feelings of professional competence and job satisfaction. The generation of empirically derived behaviours can be used to guide nursing education, practice, and research in this patient population.

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Appendix A

Tool for Identifying Nurse Experts

Disclaimer

Title of Study: Critical Nursing Behaviours in Care of the Dying Elderly in the Personal Care Home

My name is Suzanne Wowchuk and I am a student in the Master of Nursing Program, at the University of Manitoba. This is an invitation to you to participate in a research study that I am conducting as part of my program. The title of my research is "Critical nurse behaviours in care of the dying elderly in the personal care home." The purpose of this study is to identify the behaviours that nurses deemed expert by their peers identify as being central to the provision of care of the dying resident in a personal care home.. You are being invited to participate in this study because you are a registered nurse providing care in a personal care home setting. This Disclaimer form, a copy of which will be left with you for your records and reference, should give you the basic idea of what the research is about, and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this Disclaimer carefully, and to understand any accompanying information.

This research has been approved by the Education/Nursing Research Ethics Board at the University of Manitoba, and approval for access has been obtained from this facility and the Winnipeg Regional Health Authority. If you have any concerns or complaints about this project, you may contact, my thesis advisor, in the Faculty of Nursing, Dr. Susan McClement (474-9515) or the Human Ethics Secretariat at 474-7122.

There are two Phases to this study. If you agree to take part in Phase I, you will be asked to anonymously nominate from among your nursing colleagues, those that you deem to be expert in care of dying residents. You will be provided a form to help you with the nomination process. It is estimated that this process should take less than 10 minutes of your time to complete. You are asked not to sign your name on this form. By identifying the name(s) of your nursing colleagues that best fit the description outlined in each of the following paragraphs, you will be giving consent to participate in this phase of the study. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from this phase of the study at any time, and/or refrain from answering any questions you prefer to omit without prejudice or consequence. There are no known risks to you should you decide to complete this form. The information on this form is confidential, and will only be accessed by the researcher (Suzanne Wowchuk).

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Instructions for Nominating Nurse Experts

Please read each paragraph carefully and indicate the name(s) of the nurse(s) that you work with that best fit each description. You may write the names of up to three nurses for each paragraph. The same nurse may be named for more than one paragraph. You may name yourself if you feel if is appropriate.

Paragraph A

They are nurses who can facilitate the transition for dying residents from curative to palliative care. They realize that there is little they or others can do to prolong the life of the resident, but they maintain a vision of what is possible when it comes to providing comfort for dying residents and their families. They help the dying patient maintain a sense of self-esteem and dignity.

Name ______________________________

Name ______________________________

Name ______________________________

Paragraph B

These nurses are especially sensitive to the needs of the families of dying residents. They promote an environment in which the participation of the relatives in care of their family member is possible, should the family so desire. They recognize that many relatives feel a need to be helpful to the dying resident. Because they appear to have an intuitive grasp of the needs of dying residents and their families, they are able to provide terminal care in a truly remarkable way.

Name ______________________________

Name ______________________________

Name ______________________________

Paragraph C

These nurses are excellent communicators. They promote clear, rational communication between dying residents, their families and other health care team members. They are sensitive to the needs of both the resident and family to talk about their impending loss and what it means to them. They can respond effectively to the fear and anger that dying residents and their families express. They seem to be able to zero in on the accurate region of the problem.

Name ______________________________

Name ______________________________

Name ______________________________

Appendix B

Semi-Structured Interview Guide

Semi-Structured Interview Guide

*Would you describe for me a situation where you believe a student or colleague had a positive attitude toward care of the dying resident or their family (i.e., was it something they said or did?)?

*Would you describe for me a situation where you believe a student or colleague had a negative attitude toward care of the dying or their family?

*Can you describe an encounter with a dying resident and/ or his/ her family in which you feel your intervention really made a difference in the resident' outcome, directly or indirectly?

*Can you recount an encounter with a dying resident and/ or his/ her family that went unusually well?

*Can you recount an encounter with a dying resident and/ or his/ her family in which there was a breakdown (i.e., things did not go as planned)?

*Would you describe an encounter that was particularly demanding.

*Would you describe a situation that you think captures what care of the dying resident in the personal care home is all about.

Information that needs to be elicited from respondents:

*The context of the encounter (e.g. shift, time of day, staff resources).

*A detailed description of what happened.

*What were the nurses concerns at the time?

*What was the nurse thinking about as they care for that dying resident and/or their family?

*What did the nurse feel during and after the incident?

*What, if anything, did the nurse find most demanding about the incident?

Adapted from: McClement, S. (1993). Critical nursing behaviours in care of the dying adult in the intensive care unit (unpublished thesis).

Appendix C

Demographic Data Collection Tool

Demographic Data Collection Tool

I.D.# ____________ Date ____________

1. Age

   Age (years) ________

2. Gender

   Female ___

   Male ___

3. Years of experience in nursing

   Years _____________

4. Years of experience in nursing in a personal care home facility

   Years _____________

5. Most recent level of nursing education completed (please check *one*)

   a) Registered Nursing Diploma ____

   b) Post-Diploma Degree in Nursing ____

   c) Baccalaureate Degree in Nursing ____

   d) Master Degree in Nursing ____

6. Have you completed a post-basic/ specialized palliative care course?

   Yes ____

   No ____

Appendix D

One Page Summary of Study

Summary of Nursing Research Study Being Conducted

There is a nursing research project currently underway in your facility, and is being conducted by a University of Manitoba, Graduate Program student Suzanne Wowchuk, as part of the requirements for a Master of Nursing degree. The purpose of this study is to identify the critical nursing behaviours that nurses deemed expert by their nursing colleagues in care of the dying elderly residents in a personal care home describe as central in the provision of end of life care in this patient population. The following research questions are being addressed:

1. What are the behaviours that registered nurses in the personal care home deemed "expert" in care of dying by their colleagues, describe as having a positive influence on the care of the dying elderly resident in the personal care home setting?
2. What are the behaviours that nurses personal care home deemed "expert" in care of the dying by their colleagues, describe as having a negative influence on the care of the dying elderly resident in the personal care home setting?
3. What factors do expert nurses identify as facilitating their ability to provide optimal care to the dying elderly resident in the personal care home setting?
4. What factors do expert nurses identify as constraining their ability to provide optimal care to the dying elderly resident in the personal care home setting?

This study involves two phases, and registered nurses employed by this facility are being invited to participate in Phase I of the study. Phase I involves the identification of registered nurse experts in the care of dying residents. Participation in this phase of the research involves all registered nurses being invited to anonymously nominate from amongst their registered nurse colleagues "experts" in care of the dying personal care home resident. If you are a registered nurse and wish to participate in this study, you are asked to review the attached forms and complete the second page of the form. You do not sign your name on the nomination form. You may leave the completed form in the ballot box located in ________________________________. The researcher will collect the ballot box in one to two weeks, and the five nurse experts identified by their peers in this facility will be sent an "Invitation to Participate" in the Phase II of the study that involves two face-to face and tape-recorded interviews with the researcher. All names of registered nurses who participate in Phase II of the study will be kept confidential. If you have any questions about this research study, please do not hesitate to contact the researcher, Suzanne Wowchuk at telephone number .

Appendix E

Invitation to Participate

Invitation to Participate In A Nursing Research Study:

Critical Nurse Behaviours in Care of the Dying Elderly in Personal Care Homes

Dear (Potential Participant);

You have been nominated, by your nursing colleagues, as an expert in the care of residents dying in personal care homes. As a nursing expert, you are invited to participate in a study that has been designed to discover the behaviours that expert nurses in personal care homes deem "critical" in the care of dying elderly residents. The knowledge gained from this study will contribute toward the development of an expert model of nursing practice in the care of the dying elderly patient.

If you agree to participate, you will be asked to take part in a tape recorded interview, that will take approximately one to two hours, and at a later date you will be invited to critique the preliminary findings of this investigation. This critique will take approximately thirty minutes.

Please make the selection of your choice:

[___] If you wish to know more about the study prior to making a decision, please contact Suzanne Wowchuk, Telephone Number:

[___] Yes, I agree to participate in this study. You can contact me with further information.

Name: ______________________________

Telephone Number: ______________________________

Once you have marked your selection (above), Please:

1) Place the completed Invitation to Participate in the accompanying envelope (stamped and marked "confidential" and addressed to the researcher
2) Seal the envelope, and
3) Drop the envelope into the mail

Thank you for considering this invitation. A prompt reply is most appreciated.

Appendix F

Consent to Participate
In a Nursing Research Study

Consent to Participate in a Nursing Research Study: Critical Nurse Behaviours in the Care of the Dying Elderly in the Personal Care Home

I have been invited to participate in the above-titled research project. I understand that I will be one of approximately ten nurses from the personal care home setting taking part in this study. This study will investigate the critical nurse behaviours that result in positive or negative outcomes in the care of the dying elderly resident. The results will contribute toward the development of a model of expert nursing practice in care of the dying.

I have been invited to participate because I was nominated by my nursing colleagues as an "expert" in the care of elderly residents who are dying. I have at least three years of clinical experience, and I am currently involved in direct patient care. I have received a verbal explanation of the study and I have had an opportunity to have my questions answered.

If I agree I will participate in a tape-recorded interview lasting 60 to 120 minutes, scheduled for a time that will be convenient for me. During the interview I will be asked to recall situations from my nursing practice that have resulted in positive outcomes for residents and their families. As well, I will be asked to identify situations that resulted in negative outcomes for the dying resident and their family. I will be asked to recall how and why the situations evolved and my feelings during the events. I may decline to answer any questions and I may withdraw from the study at any time. At a later date, I will receive a preliminary draft of the study results and will be invited to critique the findings. This critique will take approximately thirty minutes.

I understand that there are no known risks to participating in this study and there are no costs associated with my participation in this investigation. The possibility does exist that the recounting of some of my experiences in care of the dying during the interview may be emotionally upsetting to me. In that event, I understand that I am free to stop the interview, and discuss my feelings with the researcher, or a support person of my choosing. My decision regarding participation in this investigation will not affect my employment in any way. Although I may derive no direct benefits from my participation, I have been informed that knowledge gained through this investigation will contribute toward the development of an expert model of nursing practice in the care of the dying.

I understand that my participation in the study is considered to be confidential. I will be assigned a code number, and my name will not appear on any documents or interview tape. This will protect my identity and the identity of the patients and families who will be discussed during the interview. All information collected is also considered to be confidential. During the course of the study, the interview tapes will be stored in a locked cabinet, and only heard by the researcher, the Thesis Committee Chairperson and the individual hired to transcribe the tapes. Names and identifying

/...2

Consent to Participate (*continued*)

information will not appear on the transcripts. The consent forms will be stored in the same manner, in a separate location. At the completion of the study, the tapes and transcripts will be retained for a period of seven years, following which they will be destroyed.

The results of this investigation will be published as a master's thesis and may be published in the form of a journal article. This project is being supervised by Dr. Susan McClement, RN, PhD., Faculty of Nursing, Dr. Maureen Heaman, RN, PhD., Faculty of Nursing, and Dr. John Bond, PhD., Department of Family Studies, University of Manitoba.

I understand that I may contact the researcher, Suzanne Wowchuk, at telephone number or the Thesis Committee Chairperson, Dr. Susan McClement, at telephone number 474-2515.

My signature below indicates that I am informed and that I agree to participate in this investigation.

Participant's signature Date

Researcher's signature Date

Table 1 – Summary of Previous Research Investigating Critical Nurse Behaviours in the Care of the Dying

Degner, Gow & Thomson (1991) – Critical Nurse Behaviours in the Care of the Dying		
Behaviours	**Operational Definitions:**	
	Positive	**Negative**
Responding during the death scene	Behaviours that maintain a sense of calm Behaviours that maintain family involvement	Behaviours that show the nurse's horror of the death scene Controlling behaviour that excludes family
Providing comfort	Behaviours that reduce physical comfort, particularly pain	Avoidance behaviour that results in neglect Poor symptom management due to poor knowledge base
Responding to anger	Behaviours that show respect and empathy even when anger is directed at nurse	Avoidance behaviour or angry response
Enhancing personal growth	Behaviours that show the nurse has defined a personal role in care for the dying	Behaviours that show anxiety and lack of confidence in care for the dying
Responding to colleagues	Behaviours that provide emotional support and critical feedback to colleagues	Behaviours that show difficulty in providing or receiving support or criticism from colleagues
Enhancing the quality of life during dying	Behaviours that help patients do things that are important to them	Behaviours that show lack of respect for the patient or family
Responding to the family	Behaviours that respond to family's need for information Behaviours that reduce the potential for future regret Behaviours that include family in care or relieve them of this responsibility according to what's best for the family	Ignoring the family's need for information Refusing to discuss dying and spiritual issues even when the family wants to do so Passing judgement on family decisions and family behaviours toward the dying

Continued…Table 1:

Harbeck (1995) – Critical Nursing Behaviours in Care for the Dying on Adult Medical Units

Behaviours	**Operational Definitions**	
	Positive	**Negative**
Connecting	Behaviours that promote the development of a relationship with the patient	Behaviours that are reserved and distancing Behaviours that focus on tasks
Supporting the Family	Behaviours that connect and support the family and its members	Judgemental behaviours
	Behaviours that respond to the family's need for information	Behaviours that disregard the family's questions
	Behaviours that include family in care or relieve them of this responsibility, according to their wishes	Behaviours that demonstrate lack of family assessment
	Behaviours that reduce the potential for future regret Behaviours that prepare the family for the death event	Behaviours that demonstrate disregard for patient/ family's wishes Avoidance behaviours
Providing Comfort	Behaviours that reduce or eliminate physical pain	Withholding analgesics
	Behaviours that prevent unnecessary procedures including resuscitation	Failure to anticipate needs
	Behaviours that maintain presence and spiritual well-being	Avoidance Behaviours that are flippant

Enhancing Quality of Life While Dying	Behaviours that create an environment conducive to patient/ family interactions	Behaviours that maintain a “hospital” environment
	Behaviours that promote choice and control	Distancing or avoidance behaviours
	Behaviours that promote personhood	Strict adherence to hospital policies and procedures
		Seeing a disease not a person
Responding After Death Has Occurred	Behaviours that demonstrate respect and support for the family’s realization of death	Behaviours that show lack of respect for the family and their grief
	Behaviours that create a dignified bedside scene	Behaviours that demonstrate lack of appreciation of the potential impact of the death scene
	Behaviours that demonstrate respect for the body during post-mortem care	Rough impersonal handling of the body
	Behaviours that demonstrate responding to other patients	Ignoring other patient’s need to acknowledge the death event
Responding to Feelings	Behaviours that demonstrate professionalism, respect and empathy wherever anger is directed	Responding in anger
Responding to Nursing Colleagues	Behaviours that provide emotional and concrete support and critical feedback to nursing colleagues	Behaviours that demonstrate insensitivity to colleagues’ needs
Enhancing Personal Growth	Behaviours demonstrating the development of a personal role in care for the dying and their family	Behaviours that focus on tasks rather than caring
Managerial Support	Behaviours that recognize and support nursing work	Reward only visible tasks

Continued....Table 1:

Hawkins (1995) – Dying children in the hospital setting		
Behaviours	**Operational Definitions**	
	Positive	**Negative**
Connecting	Behaviours that promote a mutual closeness Behaviours that embrace the child and family	Reserved behaviours Maintaining one's distance Behaviours that demonstrate over involvement, and loss of one's professional identity
Responding to the Family	Behaviours that support the whole family, including or relieving them of the responsibility for care according to what's best for the family Behaviour that being families together Behaviours that foster a home-like environment Behaviours that respond to the family's need for information Behaviours that reduce the potential for future regret Behaviours that support the child's/ family's cultural and religious beliefs	Passing judgement on family decisions and family behaviours toward the dying Controlling or avoidance behaviours Judgmental, controlling behaviours that exclude family members, or force them to spend time together Providing a stark room, with harsh lighting and a rigid 'hospital' atmosphere Deferring to the physician Avoiding the family's need for information Providing ambiguous or conflicting messages Defensive behaviours, in response to a family's superior knowledge Refusing to discuss dying and spiritual issues even when the family wants to do so Cultural/ religious practices that interfere with the care of the dying child

Responding to anger	Behaviours that show respect and empathy even when anger is directed at the health care team	Denigrating, or angry response Avoidance behaviour
Facilitating the transition to palliative care	Behaviours that respect and support the child's right to die with dignity	Aggressive behaviours that defy death, inflict pain and suffering, and prolong dying
Responding to colleagues	Behaviours that provide emotional support and critical feedback to colleagues	Behaviours that shoe difficulty in providing or receiving support or criticism from colleagues
Providing Comfort	Behaviours that reduce physical comfort, particularly pain	Methdological behaviours that demonstrate a lack of awareness of the child's suffering Poor symptom management due to poor knowledge
	Behaviours that satisfy the child's psychological and emotional needs	Distancing behaviours that result in psychological and emotional neglect
Enhancing the quality of life during dying	Behaviours that respond to the dying child's need for information	Withholding of information, or lying to the dying child
	Behaviours that help patients do things that are important to them	Behaviours that show lack of respect for the patient or family
	Behaviours that make dying children feel special	Detached, impersonal behaviours
Responding during the death scene	Behaviours that acknowledge the child's dying	Failure to recognize the child's dying due to poor knowledge base
	Behaviours that support the child and family as death approaches	Avoidance behaviours Avoidance behaviours that result from the nurse's discomfort with care of the dying
	Behaviours that maintain a sense of calm	Behaviours that demonstrate the nurse's horror and anguish over the death scene

Responding after death has occurred	Behaviours that supports the realization that death has occurred Behaviours that demonstrate respect for the corpse during post-mortem care Behaviours that support the family beyond the death of their child	Avoidance, or controlling behaviours that restrict the family's expression of grief Rough, impersonal handling of the corpse Avoidance behaviours
Enhancing personal growth	Behaviours that show the nurse has defined a personal role in care for the dying	Behaviours that show anxiety and lack of confidence in care for the dying

Continued…Table 1:

Helwer (1994) – Critical Nurse Behaviours in Care of the Adult Dying of Cancer in the Community

Behaviours	Operational definitions
Developing rapport	Behaviours that build relationships with the patient and family Behaviours that show respect for the patient and family Behaviours that promote patient autonomy
Providing comfort	Behaviours that reduce physical, psychological and emotional pain Behaviours that support patient's spiritual and informational needs
Responding to the family	Behaviours that respond to the family's need for information Behaviours that provide emotional support to the family Behaviours that reduce the potential for future regret
Coordinating care	Behaviours that illustrate the nurses' knowledge of available resources and willingness to access them Behaviours that demonstrate the nurse's confidence in advocating and decision-making
Responding to colleagues	Behaviours that provide emotional support and critical feedback to colleagues
Enhancing personal growth	Behaviours that show the nurse has defined a personal role in care for the dying Behaviours that show the nurse is intuitive in care of the dying

Continued…Table 1:

McClement & Degner (1995) – Critical Nursing Behaviours in Care of the Dying Adult in the Intensive Care Unit		
	Operational Definitions	
Behaviours	**Positive**	**Negative**
Responding after death has occurred	Behaviours that create a peaceful, dignified bedside scene for the family Behaviours that supports the realization that death has occurred Behaviours that demonstrate respect for the corpse during post-mortem care	Behaviours that show lack of respect for the family Judgmental behaviour that limits the time family can spend with the body Rough, impersonal handling of the corpse
Providing comfort	Behaviours that reduce physical and psychological pain	Avoidance behaviour that results in neglect of patients, particularly psychological neglect
Responding to anger	Behaviours that show respect and empathy even when anger is directed at nurse	Avoidance behaviour or angry response
Enhancing personal growth	Behaviours that show the nurse has defined a personal role in care for the dying	Behaviours that show anxiety and lack of confidence in care for the dying
Responding to colleagues	Behaviours that provide emotional support and critical feedback to colleagues	Behaviours that show difficulty in providing timely, adequate feedback to nurses
Responding to the family	Behaviours that respond to the family's need for information Behaviours that reduce the potential for future regret Behaviours that facilitate the transition from cure to palliation	Cursory explanations deferring to M.D., showing off knowledge base Controlling behaviour that limits family/ patient contact time

Table 2. **Critical Nurse behaviours in the Care of Dying Elderly Residents in the Personal Care Home**

Treating the Dying Resident, the Resident's Family and the Institutional Family with Respect and Dignity	
CARE OF THE DYING RESIDENT	
Critical Nurse Behaviour	**Operational Definition**
Promoting the Provision of Psychosocial Care	Behaviours that ensure the resident did not die alone Advocating on the resident's behalf
Coordinating Symptom Management Efforts	Behaviours that reduced the physical and psychological suffering of residents Behaviours that involved advocating on the resident's behalf Endeavouring to avoid unnecessary hospitalization of the dying resident Behaviours that shield the resident from being caught up in the stressful dynamics of difficult or dysfunctional family relationships Behaviours that involved advocating on the resident's behalf to ensure that changes in medical status were addressed and not ignored as normal changes due to old age
CARE OF THE DYING RESIDENT'S FAMILY	
Critical Nurse Behaviour	**Operational Definition**
Providing a Presence/ Respecting Privacy	Behaviours that both provide a physical presence while also being cognizant of the family's need for privacy
Breaking Bad News	Communicating to family the information regarding the worsening of a resident's condition or the death of a resident
Educating Family Members	Providing information and explanations to families about what to expect regarding anticipated changes in the resident's health status in the face of physical deterioration, and to provide details surrounding the death event itself Provide guidance to the family in the decisions they are required to make

Providing a Comfortable Environment	Creating a physical setting that was comforting, home-like and familiar to the resident and family Behaviours that attempt to make families feel more at home
CARE OF THE INSTITUTIONAL FAMILY	
Providing Emotional Support to Health Care Team	Behaviours that provide emotional support to members of the health care team following the death of a resident dies
Fielding Questions Regarding a Resident's Death	Advising residents of the death of a fellow resident
Supporting Fellow Residents After the Death	Providing support to other residents who experience a loss following the death of a fellow resident

Table 3: Demographic Information Summary

Characteristics of the Sample	
Number of Participants	**10**
Gender	**Female**

Demographic Information		
Demographic	**Mean**	**Range**
Age in Years	52.5 years	43 – 61 years
Years Experience as a Nurse	29.4 years	15 – 40 years
Years Experience as a PCH Nurse	12.5 years	10 mos – 25 years

Educational Preparation	
Highest Level Achieved	**Number of Participants**
Nursing Diploma	8
Baccalaureate Nursing Degree	2
Post-basic/Specialized Palliative Care	1