University of Alberta

The Influence of Long-Term Care Culture on Awareness of Impending Death

by

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A thesis submitted to the Faculty of Graduate Studies and Research
in partial fulfillment of the requirements for the degree of

Doctor of Philosophy

Faculty of Nursing

Fall 2011
Edmonton, Alberta

Dedication

This work is dedicated to

My Mother

Abstract

Despite their proximity to death because of advanced old age and disability necessitating institutionalization, the oldest-old have rarely been the recipients of a comprehensive palliative approach to care or the focus of palliative care research. Failure to adopt a palliative approach to care of the oldest-old, particularly for frail residents of LTC facilities, has been attributed prognostic uncertainty in the context of chronic progressive diseases and poor resident-to-staff ratios.

The culture of LTC facilities has been identified as an important factor for the development of palliative care in LTC facilities. However, research has not been undertaken to examine the influence of beliefs and values about dying and death, or contextual factors on the end-of life care provided there. This research study addresses this gap using a two-stage mixed methods approach carried out in three LTC facilities in Ontario. In the first stage, all LTC residents who died over a 12 month period were described based on a review of decedent records. In the second stage, ethnographic methods were used to uncover cultural influences on the development of an awareness of impending death among participants in three LTC facilities.

The chart review revealed that 68.1% of deaths were of the oldest old, and 63.1% were of women. Advance directives had been completed for 97.3% of the 182 decedents. Death occurred in the LTC facility for 90.1% of the 182 decedents. Death was most commonly attributed to dementia and pneumonia, or other progressive, chronic conditions. Impending death was identified and palliative measures begun when it seemed certain that death would occur within a few days or hours.

Thematic analysis of the ethnographic data revealed that a generalized awareness of human mortality was maintained until within a few days of death. Clinical awareness of impending death was acknowledged by staff and family members only when significant changes in the dying resident’s status necessitated a change in care routines. Four themes related to the influence of LTC culture on awareness of impending death were identified: (a) the belief that LTC facilities are places for living rather than dying, (b) the context of limited resources and high demands for care, (c) the belief that that no one should die alone, and (d) the belief that no one should die in pain.

This report concludes with a discussion of the findings of this research study in relation to the existing discourse on LTC facilities as places for living, and the absence of a palliative care discourse that is appropriate in the context of age-related frailty.

Keywords: oldest-old, advanced old age, palliative care, end-of-life care, nursing home, long-term care frailty

Acknowledgements

Many people have contributed to my progress throughout the challenging process of my graduate studies. Although I could never name everyone in this context, I thank you all. I would like to acknowledge some key people in particular.

Thank you to my supervisor Dr. Donna Wilson for your expressions of confidence in my ability to do this work and for challenging me to live up to them. You have provided such valuable mentorship through your attention to thoroughness, detail, and clarity. Thanks also to my committee members for challenging questions that added to the development of this work.

Thank you to all my children – Brooke, Ian, Heather, Andrew and Sarah - and your families, for support and encouragement all along the way. I am truly blessed to have all of you!

Most importantly, thank you Craig, for accompanying me on this journey – with just enough space to let me get the job done, yet close enough to catch me when I faltered.

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Chapter One - Introduction to the Problem and Its Significance

The oldest-old, persons who are aged 85 years or older, comprise the fastest growing demographic group in Canada (Turcotte & Schellenberg, 2006). Oldest-old persons constitute a distinct and important group not only because they belong to the fastest growing population group in Canada and most other developed countries (Chappell, McDonald, & Stones, 2008; Wise, 2010), but because they are highly vulnerable to failing health and reduced ability to care for themselves independently.

While many of the oldest-old continue to live in the community in their own homes or the homes of others, those who require assistance with activities of daily living and/or need skilled nursing care tend to become residents of long-term care (LTC) facilities. LTC facilities have become a common setting of supportive care for individuals who do not require acute care services in hospitals, but whose needs exceed the capacity of informal and formal caregivers in the community (Wilson & Truman, 2004). Recent trends in LTC populations include older age at admission, shorter duration of stay, and higher acuity care needs (Wilson & Truman, 2004).

Although LTC facilities are charged with providing 24 hour and 7 day a week care to the most disabled persons, they do not enjoy a reputation of providing high quality care (Armstrong et al., 2009; Ferguson, 2008). This issue may be because the heritage of LTC facilities is in poor houses, places where indigent persons were left to die with the barest minimum of care (Achenbaum, 1974). This low public perception persists today despite efforts over several decades to improve LTC facility conditions (Rahman & Schnelle, 2008).

Most of the oldest-old who are admitted to LTC facilities will reside there until they die (Goldberg & Botero, 2008). For the oldest-old, death is often an outcome of acute pneumonia, dehydration, dementia, end-stage chronic illness, and/or age-related frailty (Goldberg & Botero, 2008; Lunney, Lynn, & Hogan, 2002; Lynn, 2005; Mitchell et al., 2009; O'Connor & Bullwinkel, 2009; Wilson & Cable-Williams, 2009). The trajectories of decline commonly associated with chronic progressive diseases and advanced old-age have fewer clear prognostic markers than do defined diseases such as cancer (Bern-Klug, 2004, 2006, 2009; Murtagh, Preston, & Higginson, 2004; Wallace & Prevost, 2006). Consequently, it can be difficult to determine when someone is nearing death. In the absence of recognizable prognostic indicators, there may be uncertainty about the appropriate balance of curative, restorative, and palliative goals of care for residents of LTC facilities, and also when to start palliative care.

Palliative care emphasizes relief of suffering and attempts to facilitate the best quality of life possible for individuals and their family members when reversal or remission of illness is not possible, even when the exact time of death cannot be accurately predicted (Canadian Hospice Palliative Care Association, n. d.). The terms e*nd-of-life care* and *palliative care* are sometimes used synonymously (Health Canada, 2009). In this research report, these two terms are used interchangeably.

The oldest-old who die in LTC facilities have been overlooked in palliative care research and practice (Froggatt, 2001a). The considerable gains from the palliative care movement have benefited younger persons rather than those who have reached advanced old-age (Lynn, 2005). Palliative care tends to address end-of-life (EOL) trajectories that are common with cancer, motor neuron disease, and acquired immune deficiency syndrome rather than end-stage chronic illness or age-related frailty (Allen, Chapman, O'Connor, & Francis, 2008; Field, 1996; Murtagh et al., 2004). Recent inquiries into dying and death in LTC facilities have led to concerns about aspects of care that are of central importance in a palliative approach to care (Achterberg et al., 2010; Albinsson & Strang, 2003; Brazil et al., 2006; Costello, 2001; Evans, 2002; Forbes, 2001; Froggatt, 2001b; Hall, Schroder, & Weaver, 2002; Kayser-Jones, 2002, 2009; Kayser-Jones et al., 2003; Mitchell, Kiely, & Hamel, 2004; Mitchell, Morris, Park, & Fries, 2004; Mitchell et al., 2009; Moss, Braunschweig, & Rubinstein, 2002; Parker et al., 2005; Rodrigues, Hanlon, Perera, Jaffe, & Sevick, 2010; Shield, Wetle, Teno, Miller, & Welch, 2010; Teno, 2003; Thompson, Menec, Chochinov, & McClement, 2008; Travis et al., 2002; Travis, Loving, McClanahan, & Bernard, 2001; Vohra, Brazil, & Szala-Meneok, 2006; Wallace & Prevost, 2006; Whittaker, Kernohan, Hasson, Howard, & McLaughlin, 2007). These authors have identified inadequacies in pain and symptom management, psychosocial and spiritual care, culturally appropriate care, and attention to the needs of family members.

To date, failure to adopt a palliative approach to care of the oldest-old, particularly for frail residents of LTC facilities, has been attributed only to prognostic uncertainty in the context of chronic progressive diseases (Bern-Klug, 2006; Biola et al., 2007; Coventry, Grande, Richards, & Todd, 2005), and inadequate levels of appropriately prepared staff members (Brazil et al., 2006; Evans, 2002; Kassalainen, Brazil, Pleog, & Martin, 2007; Temkin-Greener et al. 2009; Travis et al., 2002; Whittaker et al., 2007). However, in a few instances, organizational support has been identified as a significant factor for introducing palliative care into the existing culture of LTC facilities (Forbes-Thompson & Gessert, 2005; Froggatt, 2001b).

Although the culture of LTC facilities has been identified by Froggatt (2001b) as an important factor for the development of palliative care in LTC facilities, LTC culture as it relates to palliative care has yet to receive systematic or research attention. From this researcher’s perspective, the culture of LTC is reflexively related to the deeply held assumptions, beliefs, values, and contextual factors that characterize LTC facilities as highly regulated places for care of dependent persons, most of whom are very old and nearing the end of an expected human lifespan. In addition, LTC facilities are situated within a socio-economic context that is influenced by its history as settings for the accommodation of indigent people. Furthermore, in western societies, all places of care, including LTC facilities, exist within a larger cultural context that has been described as both medicalized and death-denying and unprepared for death (Godwin & Waters, 2009; Kaufman, Shim, & Russ, 2004; Stafford, 2003).

The Contribution of this Research Study

As Chapter Two will demonstrate, there is a dearth of published research considering the assumptions, beliefs, values, and contextual factors that are inherent within the culture of LTC facilities and influence the awareness of impending death. This dissertation research study addressed this knowledge gap using a two-stage mixed methods approach. As the current data related to EOL care in LTC facilities have been insufficient for the development of a clear description of the population that dies in that setting the first step used a chart review to address the question: What are the socio-demographic characteristics of residents who die in LTC facilities? The second phase involved an ethnographic investigation to answer two questions: (a) Is awareness of impending death experienced by any or all participants in LTC? and (b) How does LTC culture influence awareness of impending death and living with that awareness for participants? Residents who were aged 85 years or older, family members of residents who were 85 years of age or older, and a variety of clinical, administrative, and support staff members, were invited into this exploration of relevant cultural influences on awareness of impending death.

Altogether, this study sought an understanding of the influence of LTC culture on awareness of impending death for the oldest-old in LTC facilities. Chapter Two critically outlines the literature relevant to this study. The research process is described in detail in Chapter Three. Findings are presented in Chapter Four and discussed in Chapter Five. Chapter Six provides a summary and conclusion to this report of research.

Chapter 2 - Literature Review

This chapter presents the findings of a critical review of literature undertaken to provide a background and context for the current research study about the influence of LTC culture on the development of awareness of impending death of the oldest-old in LTC facilities.

Multiple comprehensive searches for literature in each of the selected concept/topic areas that are listed below were undertaken using Medline, CINAHL, PsycINFO, Health Star, Ageline, and Abstracts of Social Gerontology databases within the University of Alberta library system. Searches were completed at the proposal development stage to become thoroughly familiar with the topic and to identify gaps in the existing research literature, and periodically throughout the research study to maintain currency in the subject areas. A search was also completed when the data had been analyzed and the meanings and implications of findings were in consideration. The reference lists of the retrieved articles were used to identify additional publications. A variety of current gerontology and palliative care textbooks was surveyed for relevant chapters and reference citations. Searches were also conducted for relevant grey literature on the web sites of government agencies and organizations.

The first stage of the literature search focused on the central concepts in the research topic: the oldest-old, LTC facilities, LTC culture, and awareness of impending death. Additional concepts/topics were explored in later searches as it became apparent that they were necessary parts of the context of the current research study. Eight topics in total were identified as relevant to this study:

1. The culture of long-term care facilities,
2. The oldest-old as a population living nearest to the end of life,
3. Long-term care facilities as settings for care of older adults,
4. End-of-life care in long-term care facilities,
5. Death awareness,
6. The context of awareness of death and a palliative approach to care,
7. End-of-life trajectories and transition theory, and
8. Frailty in advanced old-age.

Before revealing what is known about these eight key subjects, it is important to note that the literature searches revealed very little research related specifically to the oldest-old, and none related to the development of awareness of impending death in LTC facilities. Therefore much of the literature that is reviewed involves concepts that are relevant to the current research study, but often focused on population subgroups other than the oldest-old who reside in LTC facilities. These publications are included in this review of literature because of their contribution to understanding the current state of knowledge of relevant concepts, rather than because they provide specific points for comparison to the findings of this research study. The paucity of opinion and research literature related to awareness of impending death of the oldest-old in LTC facilities underlines the potential of the current research study to address a significant knowledge gap.

Long-Term Care Facility Culture

An initial search of the literature for a description of the culture of LTC facilities was undertaken using LTC facility and its synonyms, and culture as search terms. The few publications that were located focused on organizational support for resident-centred care and safety culture in LTC facilities. No results were located that discussed nursing homes as cultural entities, or considered patterns of assumptions, beliefs, values, and contextual factors that could be considered to constitute the culture of LTC facilities. Therefore it was necessary to explore representations of the culture of LTC in publications that did not offer an explicitly cultural perspective.

Culture has been defined as “a pattern of shared basic assumptions – invented, discovered, or developed by a given group as it learns to cope with its problems of external adaptation and internal integration - that has worked well enough to be considered valid and therefore, to be taught to new members as the correct way to perceived, think and feel in relation to those problems” (Schein, 1985, p. 9). Culture is manifest in a shared system of beliefs, values, norms, and rules that provide a foundation for regulating behaviour and expression within a group (Schein, 1985). In essence, culture is a worldview as it prescribes what is possible for members of the group (Holloway & Wheeler, 2002; Roper & Shapira, 2000). Reflexively, culture is also the product of interactions within a shared and embedded knowledge of place (Crang, 1998).

Studies of culture have deep roots in anthropological investigations of civilizations that were encountered for the first time by Europeans in the context of global exploration and colonialism. The array of beliefs and lifeways that were documented by anthropologists at that time had been unimagined in the

Western/Eurocentric world prior to their ethnographic work. Consequently, the concept of culture has come to be closely associated with diversity in race, ethnicity, beliefs, language, and rituals (Hoev, n. d.). However, Schein's (1985) explanation of culture emphasized that cultural patterns represent the contextualized beliefs, assumptions, and coping strategies that serve the purposes of specific groups in particular contexts. Hence, the concept of culture can be applied to the understanding of groups that have formed for many different purposes, including work and communal living. Long-term care facilities are places where such groups are found and thus can be described in terms their culture.

In addition to advanced old-age and communal living, elements of the context that are shared in LTC facilities include work within a highly regulated institution in which dependence, routines, and surveillance are inherent and present challenges to autonomy and privacy (Hanson, Henderson, & Menon, 2002; Powers, 2001; Timonen & O'Dwyer, 2009). As common occurrences in LTC facilities, dying and death can also be considered to be parts of the cultural context.

The culture of LTC facilities in Canada is embedded in the modern Western culture which is frequently characterized as preferring to avoid both aging and death in favour of allegiance to youthfulness and living (Chappell, Gee, McDonald, & Stones, 2003; Egan & Labyak, 2001; Kaufman et al., 2004; Lynn, 2005; Northcott & Wilson, 2008; O'Connor & Bullwinkel, 2009). Hence, LTC policies and programs are more likely to privilege prevention or management of disease, and delaying the onset of dependence, with scant attention to inevitable end-of-life decline (Abbey, Froggatt, Parker, & Abbey, 2006; Whitaker, 2010). Consequently, Western cultures are less well prepared for dying and death, even in advanced old-age and in LTC facilities.

Bruera (2004) observed that the development of a palliative care culture requires a commitment to a common set of values and sense of purpose, and concerted prolonged effort to operationalize them. Abbey et al. (2006) highlighted the significance of developing palliative approaches that take the uniqueness of the LTC facility population and traditional ways of caring in nursing homes into account. Poland, Lehoux, Holmes, and Andrews (2005) referred to consideration of the unique characteristics of a setting as reflecting the significance of *place.* Places are systems “of material production and distribution, political authority and control, social differentiation and exclusion” (Poland et al., p. 172). As places, LTC facilities are not just locations where care is rendered. Rather, the nursing home is “culture manifest” (Poland et al., 2005, p. 172). The culture of LTC involves a combination of collectively held and personal meanings in a process through which “ordinary activities and conditions take on emotional tone and moral meaning” for residents, workers, and family members (Kleinman & Benson, 2006, p. 835). Furthermore, as multiple templates can be applied to understand the same phenomenon, Froggatt, Hockley, Parker, and Brazil (2011) characterized nursing homes as contested places in that various participants, at the same time, can be understood to be patients or residents; or paid caregivers or surrogate family members, No comprehensive descriptions of LTC culture were found in a thorough search of the literature. However, several studies that reported using ethnographic methods provided descriptions of some areas of practice in LTC facilities, including EOL care practices and safety (Castle, Handler, Engberg, & Sinon, 2007; Costello, 2001; Forbes, 2001; Parker, 2011; Powers, 2001; Thompson et al., 2008; Whitaker, 2010). Each of these reports offered suggestions to improve EOL care in LTC facilities. Concerns were expressed about the adequacy of levels of staffing and staff education, communication concerning EOL issues, cultural competence in the care of residents from diverse ethnic backgrounds, emotional engagement, and responsiveness to the needs of families within the LTC facility milieu (Costello, 2001; Enes & de Vries, 2004; Forbes, 2001; Jones & Wright, 2008; Kayser-Jones, 2002; Kayser-Jones et al., 2003; Shanley et al., 2009; Timonen & O'Dwyer, 2009). No reports identifying the assumptions, beliefs and values that inform EOL care or the recognition of the impending death in LTC were found.

In a qualitative study using participant observation, Nystrom and Segesten (1994) reported that LTC residents experienced feelings of imprisonment, powerlessness, and hopelessness even though the interactions between residents and staff appeared tender, caring, and cohesive. Nystrom and Segesten's findings continue to be of interest given the difficulty of changing the task orientated and routine-driven culture of nursing homes (Gibson & Barsdale, 2003; Vladeck, 2003). More recently, in an observational study of the emotional world of a nursing home in the United Kingdom, Jones and Wright (2008) explored patterns of expression and management of negative feelings of staff members and residents in a 40 bed LTC facility. They identified a complex interaction of frustration and guilt that led to feelings of defensiveness on the part of residents and staff members. High levels of dependency resulted in restrictions in both physical activity and autonomy for residents. Despite frequent and intimate interactions among staff and residents, Jones and Wright described the emotional world of the nursing home as empty of meaningful relationships.

Froggatt et al. (2011) described the colonization of the lifeworld of residents by powerful systemic imperatives in accordance with the financial and regulatory priorities of the organization. A cultural transformation away from a medicalized and task-centred approach to a client-centred and social philosophy of care has been suggested as a means for improving the quality of care in LTC facilities (Caspar, O'Rourke, & Gutman, 2009; Robinson & Rosher, 2006; Vladeck, 2003). Stafford (2003) recognized that such a transformation in nursing homes is complicated by persistent tension between the discourses of medicine and home in LTC facilities.

Despite the desire to make contemporary LTC facilities seem more resident-centred and home-like, daily routines, protocols, procedures, obligation to regulatory requirements, and hierarchical relationships of power, contribute to the persistence of the institutionalized nature of LTC facility culture (Deutschman, 2005; Rahman & Schnelle, 2008; Vladeck, 2003). Furthermore, care providers have been socialized into work-related roles and trained to meet standards of care and efficiency that reflect economic imperatives, compliance to externally mandated standards, and a medical model of care (Froggatt et al., 2011; Parker, 2011; Stafford, 2003). As a result of these mechanisms, LTC facility culture is positioned within a highly regulated organizational and medically-oriented milieu that controls much of its reality.

Insight into LTC culture, as it develops from a synthesis of the existing literature, evokes an image of a *total institution* (Goffman, 1962). Goffman described the power of the institution to prescribe socially acceptable ways of thinking and acting through reinforcement of ways of speaking and behaving. In a total institution, all aspects of living and dying are culturally constructed according to beliefs and values that are privileged within existing relationships of power. Based on her findings in an ethnographic study, Parker (2011) reported that in Australian nursing homes, *the dying self* was one of the identities constructed for residents who were considered to be close to death. However, the beliefs and values on which the identity as one who is dying is constructed were not reported by Parker, or in other literature.

In summary, the culture of LTC facilities has not been explicitly described in the existing literature. However, LTC facilities are situated in a larger cultural context within which they are highly regulated in relation to standards that may not embrace dying and death as positive outcomes. Interactions among residents and staff are organized to reflect allegiance to life and living. Consequently awareness of the reality of dying and death may be avoided, or even denied, despite the implications for timely planning for appropriate EOL care for residents, their families, and staff members.

The Oldest-old as a Population Living Nearest to the End of Life

As indicated in Chapter 1, for the purposes of this research, the oldest-old are defined as those who have lived to be at least 85 years of age. This same definition is commonly used in current literature (Berg, Hassing, McClearn, & Johansson, 2006; Erlangsen, Vach, & Jeune, 2005; Field & Hall Gueldner, 2001; Finlayson, 2002; Grundy & Bowling, 1999; Hinck, 2007; Jeon, Dunkle, & Roberts, 2006; Levers, 2006; Nygren et al., 2005; von Heideken Wagert et al., 2005). For the purpose of this report, the oldest-old are considered to have lived to an advanced old-age. This age group is of critical interest because of its increasing numbers in modern societies and the economic implications of frailty, a state which is more common in advanced old-age than at any other age (Lunney, 2006). However, the oldest-old are not well represented in the literature. For the purpose of this literature review, the oldest-old were of interest as a group living close to the end of the expected current human lifespan of 80.4 years (Statistics Canada, 2011). Therefore searches were conducted using the terms oldest-old or advanced old-age, and dying, or death, or end-of-life.

Consistent with the well established and clearly documented demographic trend of increased longevity in the Western world, it is now common for dying to be experienced in advanced old-age (Grundy, 1997; Northcott & Wilson, 2008; Public Health Agency of Canada, 2002; Wise, 2010; World Health Organization, 2010). While their longevity speaks to their hardiness, the oldest-old are nevertheless inevitably drawing closer to the end of life, as illustrated in data. In 2008, the estimated life expectancy for Canadians aged 80 years was 10.4 years, 7.5 years at age 85 years, and 5.2 years at 90 years of age (World Health Organization, 2009). Similarly, in the United States of America, life expectancy at age 80, 85, and 90 years was 9.33, 6.68, and 4.62 years respectively (World Health Organization, 2009). Life expectancy at a given age with dementia has been found to be shorter by about one half than at the same age without dementia (Larson et al., 2004, Nepal, Brown, & Ranmuthugala, 2008). For individuals who have required relocation to a LTC facility due to poor health and increased dependency, life expectancy may also be shorter than for their non-institutionalized peers. In 1999, in LTC facilities in the province of Alberta, Canada, the average age at death was 85.6 years, and the average duration of residence in a LTC facility prior to death was 3.4 years (Wilson et al., 2009). At no other stage of the lifespan is death as predictably imminent as it is in advanced old-age. Therefore, the oldest-old can be considered to be inevitably living near the end of life. A consistent palliative care approach to care could therefore be considered to be appropriate for the oldest-old, particularly for those who live in nursing homes.

Long-Term Care Facilities as Settings for the Care of Older Adults

Long-term care facilities, nursing homes, aged care facilities, and skilled care homes are among the various terms that are used in reference to residential institutions for individuals who require supportive accommodation and assistance with activities of daily living. All of these terms were included in searches of the literature for articles about LTC facilities as places for living and dying by the oldest-old. The results of these searches contribute to the description of LTC facilities as the context for the current research study.

LTC facility staff provide supervision and assistance with activities of daily living, monitoring and management of illnesses, and health promotion (Berta, Laporte, & Valdmanis, 2005; Mathie et al., 2011; Ontario Ministry of Health and Long-Term Care, n. d.; Wilson, 2001). Residents of LTC facilities typically have greater needs for care than can be managed in the community, or in the assisted living or retirement home sector. Dementia-related cognitive impairment, incontinence, and stroke or fall-related mobility limitations are common reasons for admission to a LTC facility (Jones, Dwyer, Bercovitz, & Strahan, 2009; Registered Nurses Association of Ontario, n.d.; Trottier, Martel, Houle, Berthelol, & Legare, 2000). In general, residents of LTC facilities are older, more frail, and in need of higher levels of care now than at any other time in history (Berta et al., 2005; Mathie et al., 2011; Wilson & Truman, 2004). As many as one third to one half of LTC facility residents die within one year of admission (Forbes, 2001; Jones et al., 2009; Sidell & Komaromy, 2003).

The prevalence of dementia is a striking feature among the oldest-old, and among residents of LTC facilities. The incidence of dementia increases from 1 in 50 for those between the ages of 65 to 74 years, to 1 in 3 for those over the aged 85 years or older (Alzheimer Society, n. d.). Overall, about half of all persons with dementia live in the community with varying levels of support from informal and formal caregivers, and half reside in institutions (Alzheimer’s Society, n. d.). Dementia is progressive, with more than 95% of those afflicted receiving institutional care in the advanced stages of the disease (Lloyd-Williams & Payne, 2002; Wilson & Truman, 2004). In the United Kingdom, based on retrospective analysis of data, 62% of residents in LTC facilities were found to have suffered from dementia (Matthews & Dening, 2002). Similarly, Fries, Hawes, and Morris (1997) reported that based on Minimum Data Set criteria, 69% of American LTC facility residents suffered moderate or severe dementia. Up to 75% of nursing home residents in Canada live with some degree of dementia (Kaasalainen et al., 2007).

Women are more likely than men to become residents of LTC facilities (McPherson & Wister, 2008). In Canada, only 4% of males and 8% of females aged 65 years and older resided in nursing homes in 2006 (McPherson & Wister, 2008). However by age 85 years, 18% of males and 28% females lived in LTC facilities (McPherson & Wister, 2008). Increasing frailty and dependence, and the questionable availability of adequate formal and informal care in the community converge to increase the likelihood of admission to a LTC facility in advanced old-age (Trottier et al., 2000; Wilson, 2000, Wilson et al., 2005). While some who are admitted to LTC facilities are temporary residents for restorative or convalescent care, rehabilitation, or respite care prior to returning to the community, most become permanent residents (Chappell et al., 2003; Wilson, 2001).

The prospect of needing to relocate to a nursing home is among the most prominent worries of aging adults (Bradley, Whiting, Hendricks, & Wheat, 2010; Grundy & Bowling, 1999; Jeon et al., 2006; Scocco, Rapattoni, & Fantoni, 2006; Stafford, 2003). Perhaps the heritage of nursing homes as the last resort for the poor and indigent has contributed to lingering negative stereotypes about the quality of life and dying in contemporary LTC facilities (Chappell et al., 2008; Peace & Katz, 2003; Wilson, 2001). Efforts to address standards of care through regulation have resulted in some notable improvements such as the reduction in use of physical restraints, added opportunities for resident and family involvement in planning care and activities, creation of a less institutional appearance, and an increase in the daily allowance for food (Robinson & Rosher, 2006; Wilson, 2001). Despite these improvements, the current challenges of living and working in a LTC facility are periodically presented to the public in media reports that focus on the inadequacy of care and consequent indignity (Ferguson, 2008; Kayser-Jones, 2009; Russell, 2008). Concerns remain about the persistence of a medical model of care despite attempts to cultivate a more resident-centred and home-like approach (Abbey et al., 2006; Caspar et al., 2009; Gibson & Barsdale, 2003; Robinson & Rosher, 2006; Stafford, 2003; Tobin, 2003; Vladeck, 2003). The adequacy of staffing and the quality of staff preparation for their challenging roles are additional current challenges (Brazil et al., 2006; Kayser-Jones et al., 2003; Lo et al., 2010; Munn, et al., 2008; Vohra et al., 2006).

In addition to concern about the quality of care, relocation to LTC can be a source of worry related to the disruption of social networks, and losses of autonomy and privacy. In research studies on life satisfaction and enhancing the quality of extended life years, Grundy and Bowling (1999), Berg et al. (2006), and Timonen and O’Dwyer (2009) found that maintaining control of one’s life, autonomy, avoiding boredom, getting out, and continuing to live at home were of central importance to the oldest-old. These priorities are in stark contrast to the likelihood of experiencing "social death" in nursing homes (Froggatt, 2001a; Timonen & O’Dwyer, 2009). Social death refers to the erosion of social networks, personal agency, and autonomy as one loses physical and cognitive capacity, thus requiring long-term care.

Furthermore, residents of LTC facilities who participated in informal conversations in Whitaker’s (2010) ethnographic study reported that life in LTC facilities was mediated by their increasingly “incapable bodies” (p. 99). Similarly, Parker (2011) identified that *the bodily self* was one of four key identities through which relationships were negotiated in Australian LTC facilities. Residents in American nursing homes who participated in focus group discussions about the end-of-life in LTC facilities reported that dying and death were common and normal (Munn et al., 2008). Consequently, the LTC facility, as the last place of residence for most who are admitted there, may represent the reality of a bodily decline leading to death.

Although the proportion of deaths that occur in nursing homes is smaller than the proportion of deaths occurring in hospital (Forbes-Thompson & Gessert, 2005; Munn, Hanson, Zimmerman, Sloane, & Mitchell, 2006; Northcott & Wilson, 2008; Wilson et al. 2009), the oldest-old are more likely than other age groups to approach the end of life in a LTC facility (Fisher, Ross, & MacLean, 2000; Francke & Willems, 2005; Froggatt, 2001b; Klinkenberg et al., 2005; Meier & Morrison, 1999). In the United States of America, 58% of all individuals 85 years of age or older spend some time in a LTC facility (Meier & Morrison, 1999), and 38% of all deaths of the oldest-old occur in nursing homes (Mezey, Miller, & Linton-Nelson, 1999). Shield et al. (2010) reported that 25% of all non-traumatic deaths of older Americans occurred in nursing homes. Thirty five percent of deaths in LTC facilities in the United Kingdom (Sidell & Komaromy, 2003), and 44% of deaths in American nursing homes (Jones et al., 2009) occurred within 1 year of admission.

Based on information drawn from decedent charts, Goldberg and Botero (2008) found that the most common primary cause of death for those who died in an American LTC facility was dementia, followed by deaths due to cardiac disease, pulmonary disease, malignancies other than of the lung, and cerebrovascular accidents. Golderg and Botero were not able to compare causes of death within the LTC facility to those of residents who were transferred to hospital and died there. Although the practice of transferring residents of LTC facilities to hospital for EOL care is less common than it once was, it is likely that some residents experience much of the dying process in the LTC facility before being transferred to hospital where the death occurs. The hospital is then counted as the death place for statistical purposes (Northcott & Wilson, 2008).

In summary, the findings of this review of literature concerning LTC facilities, particularly for residents who have reached advanced old-age, confirm that dying and death are common in LTC facilities. As unavoidable aspects of the LTC facility environment, dying and death could be expected to contribute to the culture of LTC facilities.

End-of-Life Care in Long-Term Care Facilities

The literature on dying and death in LTC facilities was of central importance to this research study. Much of the literature described residents' EOL experiences in the context of existing practices, the additional challenges encountered in pain and symptom management in advanced dementia, and the perceptions of family members regarding the quality of EOL care.

Unfortunately, the quality of EOL care in LTC facilities has been the subject of considerable concern even though it is highly regulated by governing authorities in most Western jurisdictions (Field & Cassel, 1997; Forbes-Thompson & Gessert, 2005; Jones et al. 2009; Keay, 1999). As cited previously, reports have identified deficiencies in pain and symptom management, spiritual care, and culturally appropriate care, particularly in the context of dementia. Furthermore, concern has been expressed that an interventionist approach can contribute to prolonged suffering (Meier & Morrison, 1999). Consequently, there is increasing interest in EOL care within LTC facilities as a new focus within the field of palliative care (Achterberg et al., 2010; Albinsson & Strang, 2003; Brazil et al., 2006; Costello, 2001; Evans, 2002; Fisher et al., 2000; Forbes, 2001; Froggatt, 2001b; Hall et al., 2002; Kayser-Jones, 2002, 2009; Kayser-Jones et al., 2003; Mitchell, Kiely et al., 2004; Mitchell, Morris et al., 2004; Mitchell et al., 2009; Moss et al., 2002; Parker et al., 2005; Rodrigues et al., 2010; Teno, 2003; Travis et al., 2002; Travis et al., 2001; Veerbeek et al. 2008; Vohra et al., 2006; Whittaker et al., 2007).

Some think that standards of care to which LTC facilities are accountable reflect a priority to prolong life as death is represented as an adverse event (Cawthon et al., 2007; Dontas, Toupadaki, Tzonou, & Kosviki-Charvati, 1996; Hirdes, Frijters, & Teare, 2003; Ravaglia et al., 2008; Rockwood, 2005; Stevenson & Bramson, 2009). Signs such as weight loss and anorexia have been interpreted as triggers for aggressive intervention, rather than palliation within an acceptable trajectory of decline during the living-dying interval (Engle, 1998; Keay, 1999; Meier & Morrison, 1999).

It is widely acknowledged that awareness of impending death can facilitate relational care and symptom management that are consistent with the orchestration of a *good death* (Canadian Hospice Palliative Care Association, n. d.; Wallace & Prevost, 2006). However, acceptance that death is imminent may seem to be in conflict with a cultural preference to embrace restorative care and rehabilitation as goals in LTC facilities (Stevenson & Bramson, 2009; Travis et al., 2002). In an observational study over a 6 month period, Jones and Wright (2008) noted attempts to minimize the impact of the reality of death in the nursing home in practices such as moving residents away from areas through which decedents would be moved during their transfers to funeral homes. Alternatively, they witnessed only one brief conversation concerning death. They noted frequent attempts to focus on youth and living, even when the activities or conversations seemed of questionable relevance to the residents. Failure to acknowledge impending death may compromise the quality of living and dying for LTC facility residents, many of whom are among the oldest-old, and their family members if palliative care is not offered in a timely fashion (Bern-Klug, 2006; Chappell et al., 2003; Thompson et al., 2008).

In a qualitative study of the connections between structure, process, and outcomes in two nursing homes with contrasting institutional philosophies, Forbes-Thompson and Gessert (2005) found that simply complying with the standards of care as mandated by regulatory authorities was insufficient to meet the needs of dying residents. Instead, Forbes-Thompson and Gessert found that residents' (n= 56) satisfaction with the quality of their care as they approached death was related to planning, communication, and decision-making, when all of these were grounded in a philosophy and culture of care that explicitly acknowledged the reality of dying. Mathie et al. (2011) found that the development of relationships that would facilitate decision making through out the course of residence in a LTC facility was more helpful than attempting to make premature decisions about imagined, hypothetical situations. Based on formal and informal interviews, participant observation, and document review, Temkin-Greener et al. (2009) reported that improved monitoring of the quality of palliative care practices and staff education were related to better EOL processes. The presence of administrative and clinical policies related to EOL care did not, in and of itself, correspond to evidence of improved EOL care.

In summary, the literature on dying and death in LTC facilities identifies needs for considerable improvement in EOL care. Furthermore, the literature suggests that improvements will require the development of a LTC facility culture that acknowledges the realities of dying and death, and expects excellence in palliative care practices.

Death Awareness

Literature searches using the term *death awareness* combined with the terms *oldest-old, advanced old-age,* or *LTC* yielded no results. The following review is a synthesis of literature regarding death awareness in general, and includes perspectives from psychology in which the term *mortality salience* has been used in reference to awareness of the reality of death (Arndt, Greenberg, & Cook, 2002, p. 307).

Death awareness, or awareness of eventual mortality, is widely acknowledged as a challenging and unique aspect of humanity. Philosophers, psychologists, and theologians have struggled to render knowledge of mortality both comprehendible and manageable within the human lifeworld (Levi, 1998; Loy, 1997; Rosenberg & Guy, 2000). Epicurian philosophers claimed that as the self will have no experience when life ends, there is nothing about death to fear (Epicurus, cited in Levi, 1998). Alternatively, religious traditions including Christianity and Buddhism focus on death as a transition to a new state of being that can be preferable to life (Loy, 1997; Rosenberg & Guy, 2000). Religion thereby offers the possibility to neutralize the fear of death, or perhaps even welcome death.

Within psychology, terror management theory posits that death awareness or mortality salience motivates efforts to bolster self esteem, and to avoid or defend against feelings of insignificance that would otherwise be overwhelming (Arndt et al., 2002; Pyszczynski, Greenberg, Solomon, Arndt, & Shime, 2004). Terror management is thought to be accomplished principally by striving to measure up well in light of socio-cultural values (Arndt et al., 2002; Pyszczynski et al., 2004), and the development and maintenance of close relationships (Mikulincer, Florian, & Hirschberger, 2003). Both of these strategies are potentially compromised for the oldest-old who are devalued when youth is idealized and aging is feared, and whose social world has been narrowed by the deaths of peers or institutionalization. Self-control is also expected to assist individuals in avoiding death-related thoughts and fear (Gailliot, Schmeichel, & Baumeister, 2006). Efforts at self-control can result in fatigue and poorer task performance, both of which would be additionally challenging for the oldest-old (Gaillot et al., 2006). Furthermore, avoiding death-related thoughts through denial of impending death is not likely to be helpful in embracing a palliative approach to care at any age.

Although developmental progression toward the end of one’s life might be expected to influence the experience of mortality salience, the influence of age on death awareness is only minimally reported in the literature. Participants in most of the reported research on mortality salience have been young adults. However, based on two small experimental studies Maxfield et al. (2007) reported that participants aged 61 to 84 years were less judgmental concerning moral transgressions of others following thoughts of his or her own death than those aged 17 to 37 years. Very little is known about whether younger and older people respond differently in other ways to death awareness. However, Deffner and Bell (2005) found that among nurses, who are typically younger than residents in LTC facilities, higher levels of death anxiety were related to increased reluctance to discuss issues related to dying.

Dying and death were not among the critical dimensions of worry among 193 community-dwelling seniors who were 85 years of age or older in Jeon et al.’s (2006) factor analysis of elders’ self reported concerns. Worries about the consequences of declining physical abilities, loss of mobility, and difficulties related to memory loss were of most concern to participants. However, awareness of the limited life remaining was important to participants in Hinck’s (2007) phenomenological study of the meaning of time for the oldest-old (n=19) in the rural mid-western United States. Participants in Hinck’s study were uncertain about the quantity and quality of the limited time remaining to them, and were determined to make the best of each day.

Unlike terror management theorists, existential psychotherapists recognize the value of death awareness in motivating appreciation of and accomplishment in life (Colarusso, 1998; Crocker & Nuer, 2004; Griffith, 2002; Levi, 1998; Ryan & Deci, 2004; Steffen, 2007). They contend that anxiety resulting from death awareness must be acknowledged rather than avoided. This view is consistent with Heidegger’s suggestion that acknowledging the *possibility* of one’s own death opens the opportunity to create one’s way of being (Dreyfus, 1991). Alternatively, a focus on the *event* of death denies one the possibility of creating a future and living well toward death (Dreyfus, 1991).

Developmental psychologists imply that a confrontation with mortality is necessary in order to come to terms with age-related losses, including the loss of life (Erikson, 1977). Rocke and Cherry (2002) theorized that because the end of life in advanced old-age is not untimely, its anticipation is not likely to be accompanied by anger or a sense of unfairness. Rocke and Cherry theorized that the loss of many other aspects in one's relational world actually facilitates coping with one's own impending death. In the natural scheme of lifespan development, recognizing and coming to terms with one's own mortality and impending death are arguably the central developmental tasks in old-age (Erikson, 1977; Erikson, 1997).

In the context of terminal illness, the awareness of one's own impending death has been central to the discourse of palliative care since Glaser and Strauss's (1965) early research concerning the context of awareness. Yet, little is known about how awareness of impending death is developed, either in the context of unexpected life-shortening illness, or toward the end of a natural lifespan.

In summary, the concepts of death awareness and mortality salience have been of interest to psychologists as they relate to death anxiety and its' management, particularly among young and middle-aged adults. Although coming to terms with one's mortality has been recognized as the central developmental task for older adults, the literature does not address how this task is accomplished in any age group, or how healthy development can be supported. No research was uncovered that addressed death awareness as it is experienced in advanced old-age when death is predictably nigh as compared to at a younger age. This gap is of particular interest given that the oldest-old in LTC facilities are cared for by individuals who are usually considerably younger. Furthermore, the influence of LTC facility culture on the awareness of impending death has not been reported in the literature.

Context of Awareness and a Palliative Approach to Care

In this section, literature concerning awareness of dying is reviewed as a central aspect of contemporary palliative discourse. This perspective differs from the psychological perspective reviewed in the previous section. In psychology, the study of death awareness commonly relates to generalized awareness of human mortality; an abstract developmental task, or an imagined, temporally distant, and nonspecific threat of dying. However, in palliative care, the threat is real, relatively immediate, and particular for the individual and those who are close to him or her. There is considerable agreement in modern Western societies that the facilitation of a good or acceptable death requires open communication based on a realistic and shared understanding of the prognosis (Enes & de Vries, 2004; Seale, Addington-Hall, & McCarthy, 1997; Thompson et al., 2008). In fact, Twycross (2002) declared that “it is not possible to provide good palliative care without prior commitment to openness and honesty” (p. 273). However, using combinations of the key search terms oldest-old or advanced old-age, and context of awareness, death awareness, or impending death, and LTC facilities or its synonyms, no articles were identified that addressed awareness of impending death among the oldest-old in LTC facilities. The following review of related literature is offered as an orientation to the concept of awareness of impending death as an element of a palliative approach to care.

Awareness of impending death as referred to by Twycross (2002) is shared knowledge of the clinical prognosis, including an estimate of life expectancy. This awareness is based on physiological and functional parameters of the individual compared to known disease trajectories and recognized patterns of decline. On an individual level, even with relatively predictable diseases, clinical prognoses are inexact at best (Bern-Klug, 2004; Lynn, 2005). With chronic exacerbating diseases and frailty, useful prognostication may be virtually impossible (Bern-Klug, 2004; Lynn, 2005).

In contrast to empirically-based medical prognostication, Callanan and Kelly (1992) described *nearing death awareness.* Nearing death awareness refers to intuitive individualized "special knowledge about – and sometimes a control over – the process of dying" (Callanan & Kelly, 1992, p. 13) that may develop during the illness experience for some individuals. Nearing death awareness is illustrated when an individual tells others that they will not be present at an upcoming event and indeed dies, even though the clinical prognosis may not have predicted the death in that timeframe. Anecdotes of nearing death awareness emphasize the significance of symbolic language in the messages that are given about impending death (Callanan & Kelly, 1992; Conley, 2004; Nadelman, 1974). Some question whether the anecdotes actually reflect a special awareness of impending death, or are based on cognitive aberrations due to disease and its treatment (Conley, personal communication September, 11, 2008; Nadelman, 1974). Although anecdotal reports of nearing death awareness may be common among those who work in palliative/end-of-life care, in the context of positivist biomedical science, nearing death awareness seems paranormal and remains largely a matter of curiosity, if not skepticism. Studies of nearing death awareness apparently have not been of interest to funding agencies that generally support a positivist interpretation of empirical knowledge as reports of research about this phenomenon were not found.

In contrast to nearing death awareness, there has been considerable interest in the contexts of death awareness as described by Glaser and Strauss (1965). Glaser and Strauss identified the following four contexts of awareness in their seminal research involving terminally-ill hospitalized patients and their caregivers:

1. Closed awareness which is characterized by withholding information regarding the terminal prognosis from the dying individual;
2. Suspicion awareness in which the patient suspects the truth even though the prognosis has not been discussed with him/her;
3. Mutual pretense in which the prognosis is known by all concerned, yet all continue as if the patient is expected to recover; and
4. Open awareness which is characterized by shared knowledge and open communication about the reality of impending death.

Although not intended as a model to predict stage-wise progression to the context of open awareness, one might anticipate that as the disease trajectory progresses, one would move toward suspicion awareness, if not to open awareness. In Enes and de Vries' (2004) study of ethical issues experienced by nurses caring for terminally-ill elderly people, 90% of nurses believed that most of their patients knew that they were dying even if they had not been told.

However, Fried, Bradley, and O’Leary (2006) found little change in prognostic awareness in serial interviews over as much as a year with elderly individuals who were seriously ill with cancer, congestive heart failure, or chronic obstructive pulmonary disease. Likewise, their informal caregivers demonstrated little change in awareness of the consequences of disease progression for their loved ones’ prognoses (Fried et al.). Similarly, LTC facility residents in Parker’s (2011) serial interviews demonstrated little change in their views about living and dying over as much as a year during which time they experienced the deaths of peers and their own declining health. No reasons for stasis in context of awareness despite the decline in research participants’ health status were included in these research reports. However, among the possible explanations are: (a) the nature of communication between clinicians, patients, and families, (b) psychological defense against a threatening reality, and (c) participants’ choices to report an optimistic understanding of their future despite knowledge of a more limited prognosis.

Individuals may appear to communicate different levels of awareness of impending death at different times depending on their needs and goals, and their perceptions of the needs of those who are important to them under the circumstances (Copp, 1998; Hinton, 1998, 1999; Payne, Langley-Evans, & Hillier, 1996; Weisman, 1972). Thus, the context of awareness can be fluctuating and conditional (Field & Copp, 1999). As such, expressions of awareness of dying can be modified in keeping with the expectations of family members, the organization, or the institution. Individuals can self censor in order to comply with the cultural context, minimize the discomfort of others, or avoid disapproval or conflict. Consequently, open awareness can be more or less prevailing or *full* (Field & Copp, 1999; Seale et al., 1997), with full and open awareness being characterized by both mutual awareness and willingness to talk about the impending death.

Full and open awareness shares some attributes with *acceptance* as described by Kubler-Ross (1969). According to Kubler-Ross, acceptance of a terminal diagnosis is characterized by the resolution of the turmoil of the previous stages of shock, numbness and denial, anger, and bargaining. Like full open awareness, acceptance implies a willingness to engage in conversation that facilitates the completion of EOL tasks such as the resolution of relationships, completing unfinished business, and planning for care. Awareness of dying has been shown to be more common among terminally-ill patients and their families now than prior to the influence of the palliative care movement (Burns, Brown, Smith, Dear, & Craft, 2007). Nevertheless, the extent to which openness in communicating about the likelihood of dying is actually reflected in interactions between patients, families, and health care providers has been questioned in several reports concerning factors that are related to the provision of highest quality palliative care (Biola et al., 2007; Hall et al., 2002; Quill, 2000; Rodrigues & Young, 2005; Shanley et al., 2009; Thompson et al., 2008).

In Western palliative care discourse, full open awareness is considered to be important in orchestrating a good death in the context of relatively predictable terminal illnesses such as cancer (Byock & Sheils Twohig, 2003; Twycross, 2002). Disclosure of terminal prognosis begins a living-dying interval (Pattison, 1977), in which the tasks of the dying person (Corr, 1992) can be completed. However chronic exacerbating diseases such as congestive heart failure and chronic obstructive pulmonary disease, progressive degenerative diseases such as Alzheimer's Disease or Parkinson's Disease, or the prolonged dwindling trajectory of frailty in advanced old-age are characterized by prognostic uncertainty (Coventry et al., 2005; Murray, Kendall, Boyd, & Sheikh, 2005). Hence, the beginning of a living-dying interval during which death is understood to be imminent, may be difficult to identify. It would appear that less is known about the development and role of impending death awareness with prognostic uncertainty than within predictable end-of-life trajectories. This is a significant knowledge gap given that dying is likely to be a phenomenon involving chronic progressive conditions for the oldest-old in LTC facilities.

Attempts to facilitate prediction of mortality risk among nursing homes residents have resulted in the development and validation of several measurement tools (Flacker & Kiely, 2003; Hirdes et al., 2003, Porock et al., 2005; van der Steen, Mitchell, Frijters, Kruse, & Ribbe, 2007). Tools such as the MDS-Chess Scale (Minimal Data Set – Changes in Health, End-stage Disease and Signs and Symptoms) use data that are readily available from Minimal Data Set assessments that are routinely completed in nursing homes in many countries, including Canada (Flacker & Kiely, 2003; Hirdes et al., 2003, Porock et al., 2005). The advantages of being able to predict mortality are: (a) appropriate care planning with residents and their families, (b) remediation of risk factors, (c) adjusting case mix within and across care-giving facilities based on a mortality-risk model, and (d) planning for system-wide care demands (Flacker & Kiely, 2003). However, the publications that were reviewed in this search of the literature did not address the extent to which mortality prediction scales are utilized in nursing homes.

The eventual terminality of a chronic disease may not be discussed at the time of its diagnosis. Instead, the focus is likely to be on disease management and health promotion (Hines, Babrow, Badzek, & Moss, 2001). Even as chronic diseases progress, considerable uncertainty often remains about when to expect death. Mathie et al. (2011) found that elderly residents of British LTC facilities trusted that they would be adequately care for at the end of life and preferred to live day by day rather than anticipate and plan for dying and death. Consequently, the value of open awareness for EOL care planning may seem less clear in the context of progressive chronic illness and frailty than with more predictable disease trajectories. The immediate and consuming challenges of living with chronic illness may limit consideration of planning for EOL care (Hebert, Schultz, Copeland, & Arnold, 2008).

Professional caregivers may also be reluctant to provide a terminal prognosis given the uncertainty of chronic disease progression. As a result, palliative status is often identified very close to the time of death (Coventry et al., 2005; Jakobsson, Bergh, Gaston-Johansson, Stolt, & Ohlen, 2006; Lynn et al., 1996; Veerbeek et al., 2008). Hence, there may be little or no time for the resolution of relational needs or deliberation about care options. Veerbeek et al. (2008) found that death occurred within 24 hours of the dying phase having been identified in 50% of deaths in a variety of settings in the Netherlands, including nursing homes. The dying phase was considered to have been recognized if the decedent’s chart included written documentation that the individual was dying. Lynn et al.(1996) found that even on the day before their death, it was common for patients with congestive heart failure to have a prognosis of a 50% chance to live 6 months more. Similarly, in Mitchell, Morris, et al.’s (2004) study of terminal care for persons with advanced dementia in nursing home and home care settings, only 10.3% of nursing home resident participants were perceived by their physicians to have a prognosis of less than 6 months, yet all died within 1 year of admission to the study.

Jakobsson et al. (2006) also identified the challenge of prognostication in their search for indicators of a *turning point* from life-extending treatment to palliation in the health records of patients whose deaths were not sudden. Turning points were identified when entries in the medical and nursing records reflected withdrawal or failure of curative or life-prolonging interventions, and a declaration of poor prognosis, accompanied by a move to comfort care (Jakobsson et al., 2006). Thirty percent of turning points were documented on the last day of life, another 33% during the last 2 to 7 days, and 19.5% during the last 8 to 30 days. Another key finding of this study was that the turning point was identified longer before deaths due to cancer than non-cancer deaths. This difference reflects the more predictable disease trajectories of cancers, and perhaps a social construction of cancer that includes dying (Lunney, Lynn, Foley, Lipson, & Guralnik, 2003). Nevertheless, Burns et al. (2007) observed that patient and family awareness of whether the goals of care were primarily curative or palliative was often fluctuating and inconsistent even in the context of advanced cancer. Given these findings, reports from families that the deaths of their loved ones were unexpected, despite their chronic illnesses and vulnerable status, are less surprising (Forbes, Bern-Klug, & Gessert, 2000; Vohra et al., 2006).

In summary, within the palliative care discourse, and in the context of a relatively predictable disease progression, full and open awareness of a terminal prognosis has been considered desirable because it is thought to facilitate completion of EOL tasks and timely care planning. The usefulness of awareness of impending death in the context of an uncertain prognosis has been less clearly documented. The literature concerning how and when death awareness develops in the course of chronic or progressive disease or how individuals and families manage or use such awareness is sparse. There is no literature that addresses awareness of impending death among the oldest-old in LTC facilities, despite the likelihood that many will die there.

End-of-life Trajectories and Transition Theory

End-of-life trajectories and transition theory (Meleis, Sawyer, Im, Messias, & Schumacher, 2000) were identified as relevant concepts for the purpose of this research study as they focus on changing health status and orientation to the future, both of which are relevant to the development of awareness of impending death. No literature was found that elucidates the process of transition toward death within the end-of-life trajectory of frailty which is arguable the most likely one for frail and elderly residents of LTC facilities. An integration of the literature concerning these concepts as they have been studied in other contexts is presented here as they are significant components of the study of the end of life in advanced old-age that remain to be developed.

Transition theory was developed within nursing due to its utility in understanding the experiences of clients and families in the processing of both expected and unexpected life changes (Kralik, Visentin, & van Loon, 2006; Meleis et al., 2000). Melelis et al. (2000) described transition experiences as being characterized by: (a) awareness of changes that set the transition in motion; (b) individual engagement in the processes inherent in the transition, such as seeking information; (c) change and difference as both cause and effect of response; (d) flux or variation over time; and (e) uncertainty, punctuated by marker events that require focused attention.

In integrative research based on studies of a variety of client groups including family caregiving in chronic illness, motherhood, menopause, and living with chronic congestive heart failure, Meleis et al. (2000) also found that the development of skills to master the changed situation and a reformulated identity consistent with the changed situation were outcomes of the process of transition. Similarly, in their phenomenological study of the transition towards the EOL among patients with advanced cancer in Europe, Larkin, de Casterle, and Schotsmans (2007) identified the significance of identity shift, redefinition of self, and changing roles as the disease progressed. However, as transition has often been described in terms of resilience and reconstruction to accommodate a changed future, Larkin et al. proposed that transition is inadequate to describe the dynamics of a process that inevitably ends in death. Larkin et al. suggested that further research into *transience* could more adequately explain the significance of impermanence or finitude of life within a palliative context.

Research about transition in the context of EOL care has focused on the reorientation of care from curative or life prolonging goals to palliation in a variety of clinical settings (Enes & de Vries, 2004; Francke & Willems, 2005; Hines et al., 2001; Jakobsson et al., 2006; Thompson, McClement, & Daeninck, 2006), but not on the mental or spiritual processes that facilitate redefinition of self, transformation, or acceptance of transience among patients, family members, or formal caregivers. In each of the three studies reviewed below (Badger, 2005; Thompson et al. 2006; Waldrop, Kramer, Skretney, Milch, & Finn, 2005), awareness of impending death was necessary in order for a transition from curative or life prolonging goals of care to palliative care to be negotiated.

Based on observation and focus group discussions with nurses in critical care settings, Badger (2005) reported that younger age of patients, misunderstandings about the illness by family members, family discord, and inconsistent medical care decisions made the transition to comfort-oriented care more difficult. As a result of grounded theory building in the context of acute medical units, Thompson et al. (2006) reported that facilitating and maintaining a “lane change” (p. 91) from curative to palliative care was the crucial subprocess in creating a “haven for safe passage” (p. 91). Nurse-participants in Thompson et al.’s research believed that their roles in sensitively coaching, cueing, educating, and advocating for patients and families were central in dealing with uncertain prognoses, knowledge deficits among family members, and inconsistencies in the medical management of care in the absence of a shared palliative philosophy of care. Similarly, family caregivers in home-based hospice care also needed to receive and assimilate information about the illness and the meaning of its progression in order to comprehend its terminality and accomplish final transitions (Waldrop et al., 2005).

Hines et al. (2001) found that transition to a palliative approach to care for individuals with end-stage kidney disease was difficult when various members of the family reached differing conclusions about the prognosis. Lack of consistent and sensitive communication with professional care providers exacerbated the problem (Hines et al., 2001). In interviews with nurses in dialysis units, Hines et al. found that patients continued to be interested in information concerning living with dialysis even when nurses believed that the consideration of foregoing dialysis would be more appropriate. As a result, nurses felt that discussions about EOL issues were often not timely. Similarly, in a case study discussed by Crighton, Coyne, Tate, Swigart, and Happ (2008), the need to recognize and unify divergent desires among clinicians and family members was crucial in reaching a consistent approach to care. Crighton et al. characterized transitioning to EOL care as a process of becoming aware of divergent desires, probing the patient’s wishes, and accepting and refocusing on the desires of the patient.

To the extent that knowledge about changes in health and functional status can inform decisions about the adoption of a palliative approach to care, knowledge about the predictable courses of diseases and significant indicators of disease progression could be expected to facilitate the transition to EOL care planning and the completion of tasks related to life closure. Murray (2009) described three illness trajectories related to progressive chronic illnesses:

1. A predictable disease course over a predictable and relatively short time frame, with the greatest decline in functional status and self care capability confined to a short period prior to death, as with many deaths due to cancers;
2. Illness progressing over years, punctuated by periodic acute exacerbations that are survived despite their life-threatening severity, as with chronic congestive heart failure or chronic obstructive pulmonary disease. Uncertainty develops about when to expect death, despite increasing functional limitations over time; and
3. Progressive slow decline in function or dwindling from an already low baseline due to physical and/or cognitive limitations as with the frail-elderly or in dementia. Death may result from the eventual overwhelming of compensatory capacity by an infection or injury.

The latter trajectory is considered to be common in Western societies, but especially in nursing homes (Goldberg & Botero, 2008; Kastenbaum, 1995), and among those who suffer from dementia (Agich, 2003). However, no reports of research concerning transitions along a trajectory of lingering were found in a search of the literature. In the absence of recognized marker events to trigger a “lane change”, it may be less clear for patients, families, and professional caregivers when to initiate discussion about the reorientation of the goals of care to palliation. Parker (2011) recommended that preparation for decision making, rather than advanced decision making may actually be more helpful in the context of uncertain prognoses.

In summary, transition theory has been useful in predicting and recognizing progression and adaptation in the context of many changing life circumstances. It has focused on resilience and redefining the self in recognition of significant events that clearly require change or adaptation. However, transition theory has not addressed change that is gradual and leads to death, as in the end-stage of chronic diseases or frailty in advanced old-age. Consequently, little is known about how to guide or support individuals, family members, and formal care providers through the progression toward the end of life in advanced old-age and the adoption of a palliative approach to care.

Frailty in Advanced Old-Age

While acknowledging the need to avoid ageist stereotyping, it is nevertheless true that frailty must be recognized as a significant part of reality for many of the oldest-old (Agich, 2003; Havens & Finlayson, 1999; Romoren & Blekeseaune, 2003; Twigg, 2007; Whitaker, 2010; Williams, 1999). In this section, frailty in advanced old-age is described from the perspectives of biomedical science and history, and as an approach to death. While younger individuals may hope to minimize both the process and significance of the aging body, for the oldest-old, bodily changes leading to frailty are commonly manifest in less active engagement in physical activity, slowing cognitive processes, and the narrowing of their relational world (Agich, 2003; Johnson & Barer, 1997;

Romoren & Blekesesaune, 2003).

It has been a difficult task for clinicians and scientists to establish consensus about the qualification and quantification of frailty for the purposes of prevention, prognostication, clinical decision-making, and research. Consequently recent publications focus on standardizing definitions of frailty and identifying its risk factors, consequences, and measurable variables in order to facilitate a scientific, biomedical approach to treating frailty (Bandeen-Roche et al., 2006; Bergman et al., 2007; Cawthon et al., 2007; Dontas et al., 1996; Fugate Woods et al., 2005; Hirdes et al., 2003, Kaufman et al., 2004; Levers, Estabrooks, & Ross Kerr, 2006; Lustbader, 1999; Purser et al., 2006; Rockwood & Mitnitski, 2007; Song, Mitnitski, MacKnight, & Rockwood, 2004; Storey & Thomas, 2004; Walston et al., 2006; Wells, Seabrook, Stolee, Borrie, & Knoefel, 2003; Xue, Fried, Glass, Laffan, & Chaves, 2008). It would appear that frailty as an approach to the end of life has not been investigated by researchers.

Bortz (2002) concluded that given the lack of clarity concerning the concept of frailty and its indicators, reliable estimates of its incidence are impossible. Bortz claimed that attempts to quantify the prevalence of frailty to this point in time have likely resulted in underestimates of its true extent. Nevertheless, the incidence of frailty has been estimated to be as low as 5% among those who are 65 years old, and about 50% among the oldest-old (Gillick, 2001). Furthermore, Lunney et al. (2003) concluded that the mean age of the frail is 85.1 years. It is likely that frailty will be a part of the experience of a slow decline toward death for many of the oldest-old, unless an acute episodic illness overwhelms their compensatory capacities and hastens death (Bravell, Berg, & Malmberg, 2007; Lynn, 2005).

Clinical definitions of frailty have included diminished reserve capacity and increased vulnerability to stressors (Rockwood, 2005). Frailty is thought to involve multiple systems, notably the musculoskeletetal, neuroendocrine, immune, and nutritional systems, in a cascade of diminished function (Bortz, 2002). Muscle strength and oxygen transport are considered central to the syndrome (Morley, Perry, & Miller, 2002). Bortz (2002) characterized frailty as a syndrome characterized by weakness, impaired mobility, poor balance, and diminished endurance when compensatory capacity is compromised by 70%. Rockwood et al. (2002) reported that their frailty scale showed a correlation between the degree of frailty and both subsequent institutionalization and death. They quantified frailty in relation to measures of ability to walk about and perform routine activities of daily living such as feeding and dressing, continence, and cognitive status.

There is potential to reverse some aspects of frailty, particularly those related to inactivity and malnutrition (Wilson, 2004). It is not clear whether preventive measures such as regular exercise are possible given the limitations that accompany advanced chronic illnesses such as congestive heart failure and arthritis (Bravell et al, 2007; Chappell et al., 2003). Romoren and Blekeseune (2003) found that frailty among the oldest-old was less likely to be reversible than among younger seniors. They concluded that the trajectory of prolonged disability that is common with frailty among the oldest-old “often takes a serious course, particularly among women" (Romoren & Blekeseune, 2003, p. 560). When frailty cannot be reversed, it is commonly understood to predict morbidity and mortality (Bortz, 2002; Rockwood et al., 2002). Frailty is likely to predict admission to a LTC facility when needs related to impaired mobility, continence, and cognitive function cannot be met by a combination of formal and informal caregivers in the community (Trottier et al., 2000; Wilson, 2000).

Prior to the biomedicalization of aging, frailty was considered to indicate that the body was wearing out and death was to be expected (Callahan, 1987; Ferrruci, Mahallati, & Simonsick, 2006; Kaufman et al., 2004). Frailty was represented as the process of natural senescence leading to a natural death (Callahan, 1987; Ferrruci et al., 2006; Kaufman et al., 2004). Currently, death in advanced old-age, even as the conclusion of progressive dwindling, cannot be recorded as a natural death due to old-age as there is no code for natural senescence in classifications such as the International Classification of Diseases (Canadian Institute for Health Information, 2009).

As institutional care of the frail-elderly and dying was less common prior to industrialization, urbanization, and the rise of public or insured health care, the supportive care of frail elders was provided primarily by informal or family caregivers (Wilson, 2001). Presently, the care of the frail- elderly typically involves some measure of formal or paid service in addition to the support of family caregivers (Statistics Canada, 2001; Trottier et al., 2000; Wilson, 2001). It is more likely for frailty to result in relocation to LTC facilities for support for the oldest-old than at any other age (Statistics Canada, 2001; Trottier et al., 2000;

Wilson, 2001). Consequently, frailty has become of significant clinical and economic concern in Canada and in other countries with aging populations (Central East Local Health Integration Network Alternate Level of Care Task Group, 2008; Kuh & the New Dynamics of Aging Network, 2007; Markle-Reid & Brown, 2003; Wells et al., 2003). Frailty, like death, is now represented in the developing literature as a pathological condition with risk factors, signs and symptoms, and costs; all of which can be addressed, explained, and quantified to facilitate research, prevention, treatment, or rehabilitation.

Although physical and cognitive decline and dependence are the most commonly addressed elements of frailty, Gadow (1983) offered an alternative representation of strength in frailty. Gadow highlighted the inner resources that the cognitively intact but frail-elderly individuals may bring to bear on the experience of living toward the end of life. Similarly, Johnson and Barer (1997) interpreted the choice of frail elders to withdraw from activities as an adaptive strategy that enabled energy conservation for highly-valued activities. As a result, individuals were able to engage in the increased introspection that is required to accomplish the existential work of gerotranscendence (Tornstam, 2005; Wadensten, 2007). Gerotranscendence is characterized by: (a) a lessened fear of death, (b) the diminished importance of time, (c) acceptance of the mysterious dimensions in life, and (d) the increased significance of ordinary events (Tornstam, 2005; Wadensten, 2007).

In summary, frailty is increasingly being explored as a preventable and treatable condition, and not as a part of an acceptable progression toward a natural death. Progress is being made in the definition and description of frailty as a foundation for further research, policy development, and program planning. Concerns about resource allocation for care in the context of age-related frailty call attention to the prevention and treatment of frailty. Given trends in demography and morbidity, the need to understand frailty as an approach to the EOL is pressing. The challenge of understanding frailty in old-age may be as much philosophical as it is empirical, as modern societies must struggle to define the values that are relevant to the realities of living into advanced old-age, the impermanence of life, the phenomenon of a timely death, and the possibility of a scientific cure for mortality.

Chapter Summary

The purpose of this literature review was to provide an orientation to the background and context of the current research study, and to the existing evidence concerning the culture of LTC in relation to awareness of impending death. In summary, the findings confirm that the oldest-old, particularly those who reside in LTC facilities, are predictably close to the EOL. Yet, this potential for dying may not be recognized or explicitly acknowledged within the culture of LTC. The quality of EOL care in LTC facilities has been found to be deficient with respect to pain and symptom management, spiritual care, and culturally appropriate care for residents from diverse ethnic backgrounds, particularly in the context of dementia. Furthermore, when awareness of impending death develops very close to the event of death, important opportunities to prepare for dying and death may be missed. The acknowledgement of impending death, despite the uncertainties inherent in the trajectories of exacerbating chronic illness and frailty, would seem to be necessary for timely initiation of a palliative approach to care. However, there is a dearth of research reports about the development of awareness of impending death among the oldest-old who are likely to experience these EOL trajectories in LTC facilities. Therefore, the purpose of this research study is to add awareness of the influence of the culture of LTC on the development of awareness of impending death for this unique and growing population.

Chapter 3 – Methodology

This study followed a review of the conceptual and research literature related to key concepts that are inherent in the research questions. A synthesis of the literature review is provided in Chapter 2. This preparatory work was done to ensure the readiness and reflexivity of the researcher. The need for this research study was confirmed by the dearth of publications concerning the development of awareness of impending death in LTC facilities. This study explored the influence of LTC culture on awareness of impending death in advanced old-age within LTC facilities using a mixed methods design. The design was consistent with the contemporary acceptance of appropriate and creative utilization of a variety of perspectives and means to shed light on research questions, rather than strict adherence to methodologies grounded in dichotomous philosophies (Burke Johnson & Onwuegbuzie, 2004; Creswell, 2006). The research proceeded in two sequential stages:

1. A quantitative stage involving a description of the population of decedents who had lived in three LTC facilities in central Ontario. This stage was necessary in order to address a gap in the existing literature describing the population that dies in LTC facilities and thereby clarify the human context of the second stage. In addition, it provided important triangulation for the findings in the second stage. Data for this description was derived from an audit of charts of persons who died during the 12 month period ending June 8, 2009.
2. A focused, in-depth qualitative stage utilizing methods commonly

associated with ethnography; in the same three LTC facilities as in stage one. The rationale and details related to the qualitative stage of the study are provided below, following a discussion of the quantitative stage.

The Quantitative Stage

The purpose of the quantitative stage of this research study was to construct a profile of decedents who resided in LTC facilities at the time of their death. An audit of the charts of all residents who died during a 12 month period was conducted. Decedents had lived in one of three LTC facilities in a small city in central Ontario. The facilities had been recruited to reflect the trends in the LTC sector in Ontario reported by Berta et al. (2005): (a) large, proprietary, for-profit facilities outnumber not-for-profit facilities that are owned by municipal governments, religious organizations, or lay interests, (b) religious and lay not-for-profit facilities have a higher proportion of residents who are 85 years of age or older than for-profit facilities, and (c) government-owned facilities have a greater proportion of residents with higher levels of care. Differences notwithstanding, all LTC facilities in the province are subject to the same government regulations and funding allocations (Berta et al., 2005). One facility of each type was selected. Facility one was a for-profit 172 bed home, facility two was a 200 bed proprietary facility affiliated with a religious order, and facility three was a 256 bed municipally owned and operated home. There were 68, 66, and 58 deaths respectively in these facilities during the 12 month review period.

Following approval from the University of Alberta Human Research Ethics Board (see Appendix A), the ethics committees at all three facilities approved the research study. The administrators of the three facilities granted access to the electronic documentation systems in each of the facilities, and to hand-written charts in the one facility that had not fully converted to electronic documentation.

Basic descriptive statistical procedures were conducted using SPSS® (Version 12) in order to construct a description of the decedent population with respect to the following variables:

1. Gender,
2. Age at death,
3. Marital status,
4. Duration of residence (months) in the LTC facility prior to death,
5. Documented identification of power of attorney for personal care at the last Quarterly Review[1] prior to death,
6. Presence of a completed advance directive in the chart at the last Quarterly Review prior to death,
7. Level of care specified in the advance directive at the last Quarterly Review prior to death,
8. Number of transfers to hospital in the last month of life,
9. Cause of death,
10. Location of death, and

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[1] Regulations for LTC facilities in the jurisdiction where this research was conducted require that comprehensive reports of resident health status be completed every 3 months. These reports are referred to as Quarterly Reviews. Quarterly Reviews are completed electronically in the three participating LTC facilities, and the data is submitted to the provincial Ministry of Health and Long-Term Care.

11. Entries in the record suggesting awareness of a turn toward the end-of-life or impending death.

Causes of death were typically not recorded in the charts of the decedents. However, in each facility, the cause of death for most of the decedents was recorded in a journal that was called the “Death Book”. The Death Book was maintained for the purpose of knowing which deaths required notification of the coroner in keeping with legislation requiring that the coroner be notified of every tenth death in a LTC facility. Staff members reported that the causes of death were usually transcribed from the death certificate into the Death Book. Occasionally, no cause was listed in the Death Book, and sometimes two or three causes were listed for the same decedent. For the purpose of constructing a profile of causes of death among the population in LTC, all causes that appeared in the Death Book were recorded, frequencies were calculated, and comparisons were made between the oldest-old and those who died before reaching 85 years of age.

As indicated, the searching of residents’ charts for evidence of a turning point toward death was completed as a part of the quantitative stage of this research. In addition to providing quantifiable data for descriptive analysis, the charts could be considered as artifacts in that they also provided textual data in the form of words, phrases, or sentences that reflect the culture of LTC facilities. Textual data were analyzed using processes similar to constant comparative analysis which is described in the qualitative section of this chapter.

The Qualitative Stage

The qualitative component of the research study sought to explore the interaction of beliefs and values related to dying and death as they influence, and are influenced by, awareness of impending death within the culture of LTC facilities. The qualitative stage of the study resulted in a current “snapshot” of a cultural ethos and its implications for EOL care, rather than a retrospective or prospective view. This part of the study used methods commonly associated with ethnography.

Ethnography was originally developed in the early 20th century by anthropologists to learn about the worldview and lifeways of members of unfamiliar and often exotic cultures (Germain, 2001; Leininger, 1998; Parse, Coyne, & Smith, 1985; Roper & Shapira, 2000; Stuebert Speziale & Carpenter, 2007). Early ethnographers sought to experience the world as members of the culture would by participating with them over protracted periods of time in the activities of the community, engaging in dialogue with key informants, and analyzing the varied modes of cultural expression, including gestures, mime, artifacts, and language (Hoev, n. d.; Holloway & Wheeler, 2002). Although contemporary ethnographers have similar goals and use similar techniques for data collection, they often engage for shorter periods of time in a focused study of a particular cultural phenomenon within familiar cultural contexts (Angrosino, 2005; Germain, 2001; Loiselle, Profetto-McGrath, Polit, & Beck, 2004). Within the taxonomy of types of ethnographies, those that focus on a particular problem within a particular context are called focused ethnographies (Roper & Shapira, 2000). The current research study is a focused ethnography of the development of awareness of impending death within the culture of LTC facilities

Corbin and Strauss (2008) recognized that all experience is “located in and cannot be divorced from the larger events in a social, political, cultural, racial, gender-related, informational, and technological framework” (p. 8). The framework contributes structures, conditions, and processes in “diverse patterns of connectivity” (Corbin & Strauss, 2008, p. 93). The result is complex *action/interaction/emotion* with a sense of purpose and continuity, depending on how the individual perceives the situation, and the meanings that are attributed to it (Corbin & Strauss). In this research study, individuals’ expressions of awareness of impending death and its significance were the results of personal meaning-making within the context of LTC culture. Their lived experience of awareness of impending death was therefore both phenomenological and culturally constructed.

It has been common to draw strict lines between methodological approaches in qualitative research. Phenomenology is commonly used when accessing the meaning of lived experience, grounded theory for understanding processes, ethnography for developing insight into culture, and discourse analysis for revealing the ways that language is used to shape experience (Roper & Shapira, 2000). However, Corbin and Strauss (2008) recognized that adherence to exclusive methodological dogma may not be consistent with contemporary ontology and epistemology. Instead, methodology should lead to insights that serve questions of importance within the focus of the research. Corbin and Strauss emphasized the need for creativity to get deeply into complex matrices that result from the interplay of micro and macro level conditions, processes, and consequences. Consequently, the contribution of both individual and cultural meanings must be acknowledged in order to capture what can be known of the development of awareness of impending death in LTC facilities.

In the planning of this research study, it was acknowledged that claims could be made for phenomenology, grounded theory, or ethnography as the qualitative method of choice. Each of these approaches was considered in relation to this study's focus. The decision to frame the qualitative portion of this current research study as an ethnography was based on the researcher's interest in the role that LTC culture plays in developing awareness of impending death. Ethnography offered the potential to shed light on cultural influences that may otherwise have remained invisible to members of the culture. A cultural perspective directs attention to the shared system of beliefs and values, rather than to individuals' interpretations, and consequently opens an opportunity for the revision of discourse that may contribute to transformation within the cultural milieu. Hence, consistent with developing qualitative research philosophy as articulated by Corbin and Strauss (2008), this research also reflects the perspective of critical social science (Wilson & McCormack, 2006).

While the principle lens in this research was focused ethnography, it was acknowledged that participants would be sharing their own unique interpretations of the culture of which they were a part. Holmes and Marcus (2005) observed that each participant's contribution to the ethnographic record is, in fact, an individual *paraethnography*. Each paraethnography is the story of how a participant makes individualized sense of his/her experience within the culturally prescribed values and beliefs (Holmes & Marcus, 2005). Therefore, the qualitative researcher who can look through phenomenological and ethnographic bifocals will gain a better view of the phenomenon than would be possible using either lens alone. It is the task of the ethnographer to construct a synthesis of paraethnographies in order to understand the complexities of the culture.

A central element of culture is a mutually agreed upon system of communication through which social norms, personal and group identities are maintained, and social and political interaction is negotiated (Starks & Brown Trinidad, 2007). These elements of culture can be examined through the lens of critical theory which seeks to elucidate the influence of power in the social construction of experience (Holloway & Wheeler, 2002).

This study could also be described as a cognitive ethnography (Crowe, 1998; Holloway & Wheeler, 2002; Struebert Speziale & Carpenter, 2007). The intent of cognitive ethnography is to elucidate the patterns in ways of thinking about phenomena that are valued within the culture (Crowe, 1998; Holloway & Wheeler, 2002; Struebert Speziale & Carpenter, 2007). As cultural phenomena, living and dying are experienced cognitively in relation to possibilities that reflect and sustain the values, norms, and rules to which members have been socialized.

Participants. This ethnography involved residents of LTC facilities who were 85 years of age or older, family members of residents who were 85 years of age or older, formal caregivers who were experienced at work in LTC facilities, and administrative staff members. Potential participants were identified as follows:

1. Potential resident participants were identified by LTC facility staff or in the process of participant observation within the facility, and invited to participate in interviews and/or focus groups.
2. Potential family member participants were identified during participant observation, through announcements in facility newsletters, and in Family Council[2] meetings.
3. Potential formal caregiver participants and administrative staff members were identified during participant observation, recruited via posters on bulletin boards, and at meetings of the regional LTC Palliative Network[3].

Potential participants were invited to participate in interviews and/or focus groups in order for the researcher to gain an initial sense of the awareness of impending death, and later to explore developing themes and concepts. Selection criteria for all participants were that they were competent to understand the information about the study that was provided in writing (see Appendices B, C, D, and E) and verbally, make a decision regarding participation, and engage in the interview or focus group. Residents who were younger than 85 years of age were not eligible to participate. Any potential participants who were unable to explain in their own words the information that had been provided for establishing informed consent were also excluded. Consent was provided in writing, or verbally by some residents who spoke their consent in the presence of a witness

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[2] LTC facilities in Ontario receive funding from the provincial Ministry of Health and Long-Term Care for the provision of a forum for family members of residents to develop mutual support networks and engage in advocacy (Ontario Family Councils’ Program, n. d.).

[3] The Long-Term Care Palliative Network is an initiative within the Regional Palliative Care Program which is funded by the Ministry of Health and Long-Term Care. The Network provides opportunities for staff from LTC facilities to meet for educational purposes and the share resources.

who was known to and trusted by the resident (see Appendix F). In these cases, the witness signed the consent form. All participation was voluntary.

Data collection procedures. As reported earlier, cultural influences on life experience are expressed through gestures, mime, cultural artifacts, and language (Holloway & Wheeler, 2002, p. 136). As is usual in ethnographic research, data collection methods in this study drew on all of these expressions of culture using participant observation, interviews with members of the culture, focus groups, and the analysis of relevant documents and artifacts (Germain, 2001; Roper & Shapira, 2000; Streubert Speziale & Carpenter, 2007) as described later in this section.

As a result of the primacy of language in the cultural construction of experience (Crowe, 1998; Starks & Brown Trinidad, 2007), particular attention was focused on how awareness of impending death was revealed through conversation and in writing.

Participant observation. The goals of participant observation are to learn about a culture by immersing oneself in it, and to identify potential participants for interview and focus groups (Roper & Shapira, 2000). While it is debatable whether the impact of the researcher's presence can be completely eliminated, the intent of participant observation is to learn about the culture by getting close to its actual functioning without changing it (Finlay & Gough, 2003; Lipson, 1991; Roper & Shapira, 2000). A total of 82 hours of participant observation were undertaken for this research. This total included three change-of-shift meetings and listening to two change-of-shift taped reports in each of the facilities, as well as assisting in the dining room, visiting with residents, and assisting in social programs.

Interviews. As is common in qualitative research designs (Corbin & Strauss, 2008), interviews were undertaken in this research study for two purposes:

1. To engage in exploration of awareness of impending death from the perspectives of participants in the culture of LTC, and
2. To seek clarification about the meaning of the researcher’s observations from participants in the culture of LTC.

Qualitative interviews are typically open or semi-structured in nature, rather than structured and standardized as is more common in quantitative designs (Corbin & Strauss, 2008). Although the exact process in qualitative interviews cannot be predetermined (Corbin & Strauss), some examples of the questions and thoughts that were used to open the discussion with residents, family members, and care providers are provided in Appendices G, H, and I. As is common in qualitative interviewing, the researcher diverged from the interview guide in order to explore particular clues as they were uncovered and when different questions as a result of critical engagement in the process (Corbin & Strauss, 2008). Through this process, the interviews became less structured and more open as each relationship developed. By this means, the interviewer hoped to maximize participants’ control and freedom of expression (Finlay & Gough, 2003; Lipson, 1991). Nevertheless, it is acknowledged that the researcher/interviewer may have been perceived as having more power in the interaction than the participant.

Furthermore, by virtue of a preconceived research interest, the perspective of the interviewer was through a particular lens that filtered what was considered relevant or interesting from what was not. Some characteristics of that lens may have been hidden even from the researcher’s consciousness as bracketing is difficult to accomplish. Some characteristics such as age and gender are inherent in the researcher and therefore not bracketable (Streubert Speziale & Carpenter, 2007). Careful reflection and documentation of the development of thoughts and feelings throughout the fieldwork and analysis helped to bring the interviewer’s perspective into awareness so that its influence could be considered in conjunction with the interview data and its analysis. Consistent with postmodern perspectives on interviewing (Fontana & Frey, 2005), it is acknowledged that the researcher likely had some effect on the process and product of the interview. Corbin and Strauss (2008) suggested that sensitive engagement with the data and people, in contrast to an objective stance, adds to rich understanding of the phenomenon of interest.

Interviews were conducted with residents, family members, formal caregivers, and administrative staff members from each of the three participating LTC facilities. Participants chose a setting for the interview in order to maximize their comfort and convenience. Field notes were kept during all interviews after explaining to the participants that the purpose was to assist the researcher to recall significant phrases or thoughts. Consistent with common practices in qualitative research, it was expected that the number of interviews would be determined as analysis revealed saturation of the data categories (Corbin & Strauss, 2008).

Interviews were conducted with 29 staff members, 9 residents, and 12 family members. Staff participants included 3 Administrators, 3 Directors of Care, 3 Registered Nurses, 6 Registered Practical Nurses, 8 Personal Support Workers, 2 Pastoral Caregivers, a Nurses Practitioner, a Nutritionist, a Social Worker, and an Activity Director. Within these participant groups, 1 staff member, 8 residents, and 6 family members preferred not to have their interview tape recorded.

The content of the interview varied depending on the participant group and the individual's perspectives. In general, the interviews were intended to contribute to an understanding of the meaning, development, and significance of the awareness of impending death for participants in LTC culture. Although it was anticipated that members of each participant group would have some degree of awareness of impending death, their expressions of it were expected to be highly individualized and perhaps guarded or symbolic. Therefore the research proceeded with sensitivity to the potential for various members of the culture to be influenced differently by the prevailing cultural discourse, relationships of power, and individual perspectives. Given the sensitive nature of the topic, particularly for residents and families, opening questions were carefully designed to allow participants to respond according to their comfort. Generally, the initial approach was designed to build trust and interest with minimally sensitive topics, and move progressively toward more sensitive questions with this progress depending on the researcher's assessment of participant comfort and readiness. Although participants were able to end the interview at any time without consequence, none ended the interview before it had reached a natural conclusion.

Review of cultural artifacts. Throughout the research process, the researcher watched for artifacts that served purposes of importance related to dying and death and/or revealed the culture related to awareness of impending death within the three LTC facilities. Artifacts are significant beyond their utility. They construct, and are constructed, by the confluence of task-related necessity, and the economic, social and conceptual priorities that operate within the system (Hodder, 2000). Roper and Shapira (2000) reminded ethnographers to be creative in their identification of artifacts that can contribute insight into the cultural phenomenon of interest. Therefore this ethnographer endeavoured to bring an artful lens to her observation and identification of material symbols that could communicate awareness of dying death.

Mission statements, policy statements, care plans, procedure manuals, resident forms, and computerized charting systems such as the Resident Assessment Inventory are examples of artifacts for the purpose of this research. Resident records, whether compiled manually or using computer-assisted documentation systems, had been of particular interest during the chart audit component of this research as they provided quantitative data regarding the identification of turning points toward death. In addition, Progress Notes within resident records provided textual data, in the language of the LTC facility, for analysis in the qualitative stage of the research study. Objects of art and ritual such as pictures and memorial boards provided additional data. Staff members' references to items that had been present in the past but were no longer available were also considered as data. Examples of artifacts that were no longer available included a designated room for the provision of palliative care in two of the facilities and a *comfort cart* containing items for the use of family members who were keeping a vigil with a dying loved one.

Focus groups. As a research method, focus groups were once seen primarily as a quick way to access a singular cultural perspective from the distillation of data gleaned from a group of the culture's members (Kamberelis & Dimitriadis, 2005). However, qualitative research has evolved in the light of poststructural epistemology and relational ethics (Chambers, 2000; Kamberelis & Dimitriadis, 2005). Consequently, focus groups are now seen as nuclei for active respectful response by members of the group to issues of concern to them, rather than as a passive reporting structure (Kamberelis & Dimitriadis, 2005). From this perspective, groups can provide comfortable and safe environments within which members can explore diverse perspectives related to the focus. Culture is thus revealed in the shared and diverse attitudes, meanings, priorities, and processes that are expressed within groups (Chambers, 2000). Synergies among group members and mutual support have contributed to the success of focus groups in developing depth and breadth of data and interpretation (Chambers, 2000; Kamberelis & Dimitriadis, 2005; Morgan, 1993; Stewart, Shamdasani, & Rook, 2007).

The plan for this research study included the convening of a focus group for each category of participants to provide a forum for clarification and authentication of findings. Three participants were able to attend a focus group of family members. One participant attended each of two meetings that were scheduled with clinical staff members. These participants brought regrets from co-workers who had either forgotten about the meeting or had last minute commitments. Administrative staff members had difficulty agreeing on a time that would suit participants from all of the three facilities. They stated that they had had many meetings recently due to various changes that were being implemented in the provincial long-term care facility legislation and regulations. Initially, they stated a preference to have materials sent to them for review and commentary rather than try to fit yet another meeting into their schedules. However, three administrators requested to meet after reviewing the qualitative findings and a time was identified when two of them could meet. Only one attended at the appointed time. Consequently, most of the planned focus groups became second or follow-up interviews with individuals.

Field notes and reflective journaling. Field notes were maintained during the time spent in auditing charts, observing and participating in activities in the LTC facilities, and interviewing. Interview participants were asked for permission for the interviewer to jot key words or ideas during the interview to act as reminders at a later time. All participants agreed to this practice. Later on, the researcher reviewed these notes to determine what needs for clarification had arisen, or to inform the development of new questions for subsequent interviews. A journal was kept to record thoughts and questions that arose throughout the research process. These notes provided helpful reminders concerning next steps, initiated reflection about the meaning of the data as it was encountered, and contributed to the iterative process of data analysis as the research continued.

Analysis of qualitative data. The objective of the qualitative data analysis was to develop conceptual order or coding (Corbin & Strauss, 2008) of data as the basis for a thick description (Holloway & Wheeler, 2002) of the culture of LTC facilities as it relates to the developing awareness and consequences of awareness of impending death in LTC facilities.

Data analysis undoubtedly reflected the critical realist orientation of the researcher (Archer, Bhaskar, Collier, Lawson, & Norrie, 1998; Clark, Lissel, & Davis, 2008). Consequently, the data analysis facilitated the development of insight into *a truth* that could be accessed within the culture at a point in time, not the absolute and objective truth. In addition, this data analysis was influenced by a critical perspective that was sensitive to the effects of power relationships, marginalization, and vulnerability. Thus, the resulting description of the culture of LTC facilities is informative rather than generalizable. It sets the stage for later theory building about the development of awareness of impending death in LTC that is grounded in a culturally informed perspective.

As is common in qualitative research, data analysis began and continued iteratively with data collection in a process of constant comparative analysis (Boeije, 2002), a process that is described in more detail below. The research process was inductive, with the findings at each step directing the next steps in data collection. Much of the data is textual as it was transcribed from taped interactions or field notes (Silverman, 2000). It must be acknowledged that participant’s words reflect meanings that are uniquely individual, as well as embedded in the culture. Therefore, each participant’s contribution can be considered as that person’s own account of the culture, or a *paraethnography* (Holmes & Marcus, 2005). In essence, the ethnographer must create a meta-synthesis of the paraethnographies in order to discern how awareness of impending death is culturally constructed (Holmes & Marcus, 2005).

The principle processes that were used to accomplish the analysis of data in this research study were questioning and making comparisons, with particular attention to words and phrases used by the participants. Corbin and Strauss (2008) identified three types of questions and their respective uses:

1. Sensitizing questions are used to connect the researcher to the phenomenon by generating possibilities related to the data. Examples of sensitizing questions include: (a) What is the issue here, (b) What were the conditions when that happened, (c) How is this the same or different form other examples of this sort, (d) How are mechanisms of social control active in this event, and (e) How is social status active in these observations or data;
2. Theoretical questions help to reveal relationships between concepts. Examples include: (a) What conditions and consequences tend to occur together, (b) What conflicts are inherent in these observations/data; and
3. Guiding questions provide direction in the research process such as in the rationale for sampling.

Making comparisons also involves asking questions in order to compare one datum with the others, and concepts with each other in order to understand the conditions and consequences that make up the phenomenon (Corbin & Strauss, 20008).

Boeije’s (2002) approach to making constant comparisons (see Appendix I) was used as a guide in this data analysis. Boeije recommended that questions should seek to find the core messages, consistencies, inconsistencies, and themes within each interview, among interviews from within the same participant group, and across different participant groups. This process of considering the meaning of each datum within a single data source, and across all the sources has been called *decontextualizing and recontextualizing* of the data (Corbin & Strauss, 2008). In this research, the goal of data analysis by this means was to craft a thick description of LTC culture as it relates to awareness of impending death, thus providing a foundation for theory building in the future.

Assuring rigor in the research process. Criteria for the assessment of rigor in qualitative research continue to be the subject of considerable critique and revision (Corbin & Strauss, 2008; Morse, Barrett, Mayan, Olson, & Spiers, 2002; Smith & Deemer, 2000; Smith & Hodkinson, 2005). The result has been the generation of a multiplicity of criteria, standards, and guidelines reflecting a variety of interpretations and priorities, each intended to confirm the merit of qualitative research from its conception to the representation of its findings. Whittemore, Chase, and Mandle (2001) summarized the challenges for quality assurance in qualitative research as being related to:

1. The appropriate alignment of epistemology and methodology with philosophical stance and the interpretation of data, and
2. Creative, yet substantiated and rigorous analysis and interpretation.

Whittemore et al. claimed that “elegant and innovative thinking can be balanced with reasonable claims, presentation of evidence, and the critical application of methods” (p. 527).

After years of immersion in the development of qualitative research theory and methodology, Corbin and Strauss (2008) offered a simple test of the rigor of qualitative research:

1. Are the findings believable?
2. Do the findings provide useful insights?

These post hoc considerations are necessary but not sufficient to satisfy Morse et al.’s (2002) expectation for verification of trustworthiness during the research process, rather than just in relation to its results. To accomplish verification of quality in the research process, Morse et al. called for methodological coherence, appropriate sampling initially and as the research progresses, iterative data collection and analysis, and theoretical thinking. The same key concepts for formative validity are inherent in the conditions and criteria that Corbin and Strauss (2008) identified as being necessary to foster quality in the final analysis. Among them are:

1. How did sampling occur initially and theoretically?
2. What data indicated the major categories in the analysis?
3. What were the grounds for statements of relationships?
4. How were negative cases integrated in the analysis?
5. Is methodological consistency apparent?

This study was conducted with sensitivity and attention to both process and post hoc evaluation. The strategies were used to achieve quality:

1. Documentation of the process, including philosophical stance, assumptions, decisions, actions, consequences, personal reflections related to the process including biases, and questions in field notes and reflective journaling,
2. Ensuring that the duration and depth of engagement supported sampling and thorough observation,
3. Attention to variations, including negative cases in the data,
4. Providing descriptive detail to support analytical statements,
5. Consultation with peers and supervisor to augment the expertise of this neophyte researcher, and
6. Member checks to ensure accuracy in understanding the interview and focus group communications. This was accomplished via email, telephone conversations, a focus group, and return visits to individuals depending on their preferences.

Ethical Considerations

In this section, ethical considerations that were relevant to this research are discussed with attention to the LTC facility residents, family members, formal caregivers and administrative staff members. The vulnerability, privacy, needs, and rights of LTC residents called for particular concern. Ethical consideration of any research involving human subjects is influenced by the legacy of interventionist clinical trials that disregarded basic ethical principles, sometimes with regrettable consequences (Online Ethics, n. d.). Consequently, the requirement for fully informed consent by participants, without duress or negative consequences, and the weighing of risks and benefits to ensure protection from harm have become the cornerstone of research ethics. These measures reflect the bioethical principles of autonomy, beneficence, non-maleficence, and justice (Beauchamps & Childress, 2001). In keeping with these principles, careful deliberation by the University of Alberta Human Research Ethics Board was both warranted and expected with respect to this research study.

Principled ethics serves the needs of research well, assuming that potential participants are competent to comprehend and make decisions. However when participants are vulnerable by virtue of age, infirmity, dependence, and/or impaired cognitive capacity, as are many of the oldest-old in LTC facilities, extra care must be taken to ensure an ethical relationship between the researcher and research participants. Ethical considerations may be further complicated when the development of a relationship, rather than the maintenance of objectivity, is an important aspect of conducting qualitative research (Jokinen, Lappalainen, Merilainen, & Pelkonen, 2002; Madjar & Higgins, 1996). Strict adherence to biomedical principles as the test for ethical soundness increases the risk that vulnerable populations, including the oldest-old, will be excluded from research. Consequently they may be excluded from the benefits of evidence-informed practice (Barron, Duffey, Byrd, Campbell, & Ferrucci, 2004).

There is surprisingly little literature addressing the ethical considerations of particular concern in qualitative research with frail-elderly individuals. However, Madjar and Higgins (1996) recommended that the moral conduct of research in nursing homes is best served by a combination of approved, objective protocols and the researcher's discretionary judgment in context, all informed by the ethic of care. Such an approach involves:

1. Balancing objective and empathic listening,
2. Non-judgmental relationships, and
3. Nonhierarchical relationships characterized by a positive attitude to participants, open-mindedness, and a willingness to engage reciprocally (Jokinen et al., 2002).

In their account of the processes involved in ethical qualitative research with terminally-ill patients and their caregivers Wright and Flemons (2002) recommended:

1. Giving precedence to the needs of the participants,
2. Understanding participant observation as an attempt to experience the intersubjectivity between the participant and researcher, and
3. Treating interviews as conversations in which there is an invitation, not a requirement, to explore subjective experience.

Residents of LTC facilities are considered to be vulnerable as a result of the likelihood of physical and cognitive frailty, dependence, and compromised decisional competence (Agich, 2003; Barron et al., 2004; Jokinen et al., 2002). Cognitive competence is of particular concern given the need for the provision of informed consent to participate in this research. Furthermore, the process of developing meaningful consent can be complicated by the potentially worrisome nature of detailed documents, complex explanations, limited reading skills, and fear of unknown consequences or loss of control (Madjar & Higgins, 1996). Furthermore, written information and providing a signature can prove difficult for potential participants who experience visual challenges, or who are concerned about signing official documents.

Jokinen et al. (2002) suggested that verbal information and consent can be more appropriate tools for arriving at *real consent* than the more common written consent. Real consent is manifest in the participant's willing engagement with the researcher. Real consent requires ongoing confirmation throughout each interview to maintain its validity (Jokinen et al.). As a negotiated process founded in the ethic of care, real consent is consistent with the respectful approach that is intended in the open and semi-structured interviews that were part of this research. In fact, several residents did not want to read the information or sign the consent form, but were very interested to hear about the research and eager to engage in the interview. Often, with both residents and family members, the process of providing information prior to the signing of consent moved naturally into discussion of the topic. In these cases, it was necessary to call a pause to get the consent form signed, followed by a resumption of the discussion.

The degree of risk associated with participation in this research was considered to be low for all three participant groups. Only one family member became emotional while she spoke of her husband's declining health. However, when offered the options of pausing, ending the interview, or continuing the interview; she chose to continue. The interview process was primarily open, allowing participants to have considerable control in determining the direction and depth of their participation. Although the researcher was prepared to direct participants to appropriate resources such as bereavement programs, chaplaincy, and counseling services in the community; no need for referral arose in the course of the interviews.

Although the researcher had no intention to act in any direct therapeutic capacity with participants, several family members spoke about it having been helpful to talk. In research to determine the degrees of stress and help resulting from talking about death, dying, and bereavement; Emanuel, Fairclough, Wolfe, and Emanuel (2004) found that 88.7% of terminally-ill patients (n=988) and 89.7% of caregivers (n=915) reported that the interview had caused little or no stress. Approximately half of these participants found that the interviews were at least somewhat helpful even though they were not intended as therapeutic interactions. Additionally, as there is some evidence that elderly residents of LTC facilities may actually suffer as a result of lack of opportunity to speak about their losses and about being near the end of their lives (Black & Rubenstein, 2004), participation in this research may have offered direct, albeit unintended, benefit to participants. The potential for indirect benefits lays in the possibility for participants to enjoy the satisfaction of altruistic contributions that may benefit others, or the experience of engagement in a novel event (Souder, 1999).

The following processes and procedures were also intended to facilitate the ethical conduct of this study:

1. Participants who were residents, family members of residents, or administrative and clinical staff members of LTC facilities were adults and

had to be able to understand the information that was provided in the process of negotiating consent. They were volunteers and provided informed consent.

2. Potential participants had the opportunity to ask questions and receive responses at any time in the research process. The researcher took particular care with resident participants to determine their ongoing willingness to engage in the interview process.
3. Details of the aims of the study and participant involvement were discussed with each participant, with attention to language and processes that respected the individual’s cognitive strengths and challenges.
4. Verbal consent was most appropriate with most of the resident participants. Verbal consent was witnessed by a competent adult who was known to and trusted by the participant. Witnesses signed the consent form to attest to the process of informed consent and willing participation of the resident.
5. Participants were able to withdraw from participation at any time without explaining their reason, and with no negative consequences.
6. The interviewer was sensitive to behavioural cues suggesting that the interview should be paused or ended.
7. The interviewer was aware of local resources to support participants if any had requested support related to any issues that arose as they participated in the interviews or focus group.
8. Participants were encouraged to set their own boundaries with respect to

the extent of personal information they shared in interviews and/or focus group.

9. All data were used only for approved research purposes.
10. No personally identifying information was included in any stored data or research reports.
11. Tape recordings, transcripts, field notes, and memos were treated as confidential material in all processes including storage, transport, and word processing.
12. Participant observation provided an opportunity for residents, family members and formal care providers to develop a sense of familiarity and trust on which to base their decision about whether to engage in an interview.

Chapter Summary

This chapter has described the mixed-methods process that was used to develop knowledge of the influence of the culture of LTC facilities on awareness of impending death among the oldest-old who resided in three nursing homes. The research was planned to proceed in two stages in order to produce a comprehensive and rich description of the population that lives and dies in LTC facilities, and the culture of LTC facilities as it influences the awareness of impending death. The initial quantitative stage utilized statistical description of data derived in an audit of records of LTC residents who had died during the previous year. The qualitative stage was an ethnographic study. The results of this research are reported in Chapter 4.

Chapter 4 – Results

The findings of this research study, concerning the development of awareness of impending death within LTC culture, are presented in two sections in this chapter. First, to highlight the population that dies in this setting, a description of a group of decedents who died during a 12 month period in three LTC facilities in a small city in central Ontario is provided. Data to support this description were obtained through an analysis of decedent charts. This chart review also provided data on the documentation of staff members' awareness of the impending deaths of those residents. In the second section, the findings from an ethnographic exploration of assumptions, beliefs, values, and contextual circumstances that influence the development of awareness of impending death within the culture of LTC are presented. Altogether, these findings inform the discussion about the influence of the culture of LTC on awareness of impending death among the oldest-old in LTC facilities that follows in Chapter Five.

Chart Review Findings

In this section, the population that died in the three LTC facilities is described with respect to select socio-demographic variables and common causes of death. Comparisons of select variables by age group (younger than 85 years at death and 85 years or older at death) and gender are also presented. In addition, data derived from the Quarterly Reviews and narrative Progress Notes contained in the charts are presented because they contribute to an understanding of awareness of impending death in LTC facilities.

One hundred and eighty two decedents were identified in the records of the three LTC facilities over the 12 month study period. Full and complete data relating to all socio-demographic variables were available in all of these records. Data were entered into a SPSS® (Version 12) spreadsheet, and analyzed as indicated in the research plan that was described in detail in Chapter Three. The results are displayed by age group in Tables 1 and by gender in Table 2.

Of the 182 decedents, 68.1% were among the oldest-old. Women were more likely than men to die in the LTC facilities (63.3% women vs. 36.8% men).The mean age at death for all of the 182 decedents was 86.8 years. The mean age at death was older for women than for men (88.3 years vs. 84.2 years). Among the oldest-old, the mean age at death was 90.8 years Overall, 62.6% of the 182 decedents were widowed, but among the oldest-old, 71.5% were already widowed when they died. Women were more likely to be widowed at the time of death than men (73.0% vs. 44.8%). The duration of residence in the LTC facility was 34.6 months for younger decedents, and 38.3 months for the oldest-old. Fifty percent of all the deaths occurred within 3 years of admission to the LTC facility; 20.9 % of all deaths occurred within the first year.

As shown in Table 1, powers of attorney for health care were present for most residents in both age groups (96.6% younger and 96.8% oldest-old). There was a high rate of completion of advance directives at the last Quarterly Review prior to death for both age groups (96.6% younger and 97.6% oldest-old). Changes in advance directives were frequently recorded in narrative Progress Notes when the resident was deemed palliative by the attending physician. With only one exception, notations in the Progress Notes indicated a change to a less aggressive or interventionist approach to care. Without exception, when death occurred within the LTC facility, the EOL care was consistent with the advance directive. More aggressive or interventionists levels of care were more likely to be included in the advance directives of residents who were younger than 85years of age compared to the oldest-old.

Table 1

Summary of Socio-demographic Chart Review Findings by Age Group

Variable	**All (n=182)**	**Younger than 85 years (n=58)**	**85 years or older (n=124)**	**Comparative statistics**
Mean age at death (years)	86.8	78	90.8	
S.D.	7.6	5.9	4.1	-
Range	57-101	57-84	85-101	
Gender (%)				χ2=13.8
Male	36.8	56.9	27.4	df=1
Female	63.2	43.1	72.6	p=.000*
Total	100	100	100	
Marital status (%)				
Married	29.1	43.1	22.0	χ2=168.725
Widowed	62.6	46.6	71.5	df=3
Never married	6.6	8.6	4.9	p= 000*
Separated/divorced	1.6	1.7	1.6	
Total	99.9	99.9	100	
Power of attorney (%)				
Identified	96.7	96.6	96.8	
Not identified	3.3	3.4	3.2	-
Total	100	100	100	
Advanced directive (%)				
Present	97.3	96.6	97.6	-
Not present	2.7	3.4	2.4	
Total	100	100	100	
Level of advance directive (%)				
None	0.5	0	0.8	χ2=146.626
One	13.2	8.6	14.8	df=4
Two	48.9	39.7	54.1	p=.000*
Three	31.9	41.4	27	
Four	5.5	10.3	3.3	
Total	100	100	100	

Transfers to hospital in month prior to death (%)				
None	69.8	53.4	77.4	χ2=220.154
One	25.3	34.5	21	df=3
Two	3.8	8.6	1.6	p=.000*
Three	1.1	3.4	0	
Total	100	100	100	
Location of death (%)				
LTC facility	90.1	87.9	91.9	-
Hospital	9.9	12.1	8.1	
Total	100	100	100	
Duration of residence prior to death (months)				
Mean	38.4	34.6	38.3	t=-276
S.D.	28.3	28.1	26.3	df=180
Median	38	33.5	38.0	p=0.783
Range	1-130	1-124	1-130	
Proportion of deaths by year since admission (%)				
1 year	20.9	20.7	21.0	
2 years	17.6	17.2	17.7	
3 years	11.5	13.8	10.5	-
4 years	20.3	24.2	18.5	
5 years	11.6	8.6	12.9	
Causes of death (%)				
Dementia	25.6	23.0	27.2	
Pneumonia	20.7	26.2	17.5	
Renal failure	6.7	6.6	6.8	
Congestive heart failure	4.8	8.2	4.3	-
Coronary artery disease	4.8	4.6	5.0	
Chronic obstructive pulmonary disease	6.1	8.2	4.9	
Multi-system failure	2.6	4.6	1.4	
Myocardial infarction	2.6	5.7	0.7	
Natural causes	13.6	4.6	19.2	

* indicates a significant difference

Documented Contributing Causes of death. As shown in Table 1, dementia and pneumonia were the two most common contributing causes of death in both age groups. In addition, renal failure, congestive heart failure, coronary artery disease, chronic obstructive pulmonary disease, multi-system failure, and myocardial infarction each contributed to death for less than 7% of deaths. Many other causes, for example, Parkinson’s disease, atrial fibrillation, and urosepsis were also identified for only one or two deaths in any age group. Deaths attributed to cancers were unusual. There was one death each for cancers of the breast, colon, lung, and prostate.

Death was attributed to “natural causes” in 13.6% (n=31) of entries in the Death Book. The Death Book contained data that had been transcribed from the death certificates completed by the attending physicians. In 12 of the 31 cases, death was attributed to natural causes alone. Additional causes were identified in the remaining 19 cases. These causes included pneumonia, dementia, respiratory failure, renal failure, and multi-system failure. Natural causes were cited in 4.6% of deaths among younger decedents and 19.2% of deaths of the oldest-old.

Most deaths (90.1%) occurred within the facility rather than in hospital or elsewhere. Men were more likely than women to have been transferred to hospital at least once during the last month of life (40.3% vs. 25.3%), and also more likely to die in hospital (13.4% vs. 7.9%). It was more common for younger residents to have been transferred to hospital at least once in the month prior to death than for the oldest-old (46.5% younger vs. 22.6% oldest-old were transferred to hospital). Details and comparative statistics related to these findings can be found in Table 1 and Table 2.

Table 2

Summary of Socio-demographic Chart Review Findings by Gender

Variable	**Male (n=67)**	**Female (n=115)**	**Comparative statistics**
Age at death (years)			t=-3.593
Mean	84.2	88.3	df=180
Standard deviation	6.7	7.7	p .000*
Age group (%)			χ2=14.761
Younger than 85 years	49.3	21.7	df=1
85 years or older	50.7	78.3	p=.000*
Total	100	100	
Advanced directive			
Present (%)	96.6	97.6	-
Not present (%)	3.4	2.4	
Total	100	100	
Marital status (%)			
Married	47.8	18.3	χ2=168.725
Widowed	44.8	73.0	df=3
Never married	6.0	7.0	p=.000*
Separated/divorced	1.5	1.7	
Level of advance directive			
None (%)	0	0.9	
One (%)	6.0	17.4	
Two (%)	47.8	49.6	χ2= 146.626
Three (%)	41.8	26.1	df=4
Four (%)	4.5	6.1	p=.000*
Transfers to hospital in month prior to death			
None (%)	59.7	75.7	χ2=220.154
One (%)	31.3	21.7	df=3
Two (%)	6.0	2.6	p=.000*
Three (%)	3.0	1.6	
Total	100	100	
Location of death			χ2=266.121
LTC facility (%)	86.6	92.2	df=1
Hospital/other (%)	13.4	7.9	p=.000*
Total (%)	100	100	
Duration of residence prior to death (months)			
Mean	34.6	40.6	t=-1.392
S.D.	26.0	29.5	df=180
Median	33.5	38.0	p=0.166
Range	1-124	1-130	

* indicates a significant difference

Awareness of impending death. The charts were also searched for evidence that staff members were aware of impending death. It was expected that this evidence would be found in the narrative Progress Notes that were kept for each resident or in the report of the last completed Quarterly Review prior to the death of each resident. One item in the Quarterly Review documented the current *level of support* required by the resident as compared to the level of support required at the previous Quarterly Review (more support, less support, or no change). Staff members reported that they interpreted this to mean a comparison of the amount of time they spent caring for the resident from one quarter to the next. Data reporting on the required level of support were available in two of the facilities. In 58.2% and 43.5% of cases in these two facilities, it was documented that there had been no change in the level of support required. The need for more support at the last Quarterly Review prior to death was documented in 32.8% and 50.7% of records. It could not be determined from this data source whether an increase in the level of support required was temporary, or part of an irreversible decline toward death.

The Quarterly Review also documented whether the resident was considered to be terminally ill. In two facilities, no one was identified as being terminally ill at the last Quarterly Review prior to death. In the third facility, only 1 of 58 residents had been documented as terminally ill at the last Quarterly Review prior to death.

In all three facilities, the Progress Notes section of the residents' charts was searched for documentation of unusual events or changes in condition. Only registered staff wrote in the Progress Notes at two of the facilities. At the third facility, unregulated care providers called Personal Support Workers (PSWs) also wrote in the Progress Notes. Notes were commonly written about new symptoms, falls, fall-related follow up, challenging behaviours or verbalizations, isolation status during outbreaks of infectious diseases, communications with family members related to falls or other mishaps, and discussions concerning care planning such as the revision of an advance directive between Quarterly Reviews.

Revisions in advance directives were common at the time of a change in condition such as increased lethargy, infection, or declining intake of food and fluids. The change was usually to as less aggressive level of intervention. Only one change to a more aggressive approach was identified in the advance directive. Documentation about discussions of changes in condition with family members usually referred to the resident's "decline," and never included the words dying or death. However, according to the Progress Notes, some residents verbalized their readiness or wish to die to staff members using unequivocal language such as in the following exemplars appearing in the Progress Notes:

"I want to die. I'm ready to go" (92-year-old woman 1 day prior to death);

"Can someone come with me to buy my coffin" (81-year-old woman 9 months prior to death);

"I don't want to eat. I want to die" (79-year- old man 1 day prior to death);

"I'm dying of loneliness but nobody cares" (87-year-old man 1 month prior to death);

"I wish I could die. I don't want to go to hospital" (94-year-old woman 5 years prior to death); and

“Let me go – I’m ready” (88-year-old man 1 ½ years prior to death).

In a number of Progress Notes, it was recorded that family members had reported having been told by their spouse or parent that he/she was ready to die:

“Daughter says father has said he is ready to go”; and

“Resident told son he wants to die.”

In three note-worthy instances, the opinion of a family member who held the power of attorney for health care decisions had apparently taken precedence over the resident’s stated wishes. In these cases, the residents had expressed the desire for no investigations or hospitalizations, but were nevertheless sent to hospital for cystoscopy, radiographic imaging, or colonoscopy. All three died within a few days of these investigations.

In a small number of Progress Notes, the unregulated care provider’s interpretation and response to residents’ verbalizations about dying, and the time involved to complete the intervention were documented. According to the Progress Notes, 3 to 5 minutes were involved per instance in providing reassurance. In one instance, a 93-year-old woman who had multiple myeloma and lung cancer rang her call bell to report trouble swallowing, and said she was dying. The unregulated care provider recorded that she “reassured resident that she is fine.” A month later, the same resident was reassured that she was “healthy” because her vital signs were normal, despite her complaints about shortness of breath and difficulty swallowing. She died two months later.

In another pattern of response to verbalizations about dying, unregulated care providers used a documentation format that was more commonly used to record disruptive or aggressive behaviours. For example, “resident rang 3 times in 60 minutes – said he is dying – really just wanted company. Resident told not to ring unless there is something to ring about.” In a notation one year later the same resident is quoted as saying “I am dying of loneliness and no body cares.” He died 1 month later, with the causes of death listed as dementia, pneumonia, and end stage renal disease. He had been “deemed palliative” 7 weeks prior to his death.

In all three facilities, it was rare for any documentation to indicate that a resident was considered to be palliative as much as 7 weeks prior to death. Typically, palliative status was not identified until the last week prior to death, and usually only a day or two before death. A commonly documented order of events began with the recognition of a change in condition such as increased lethargy and decreased oral intake which resulted in a call or fax to the physician. The resident was then “deemed palliative” by the physician. Orders for morphine for pain and an anticholinergic medication to dry secretions almost always accompanied this palliative designation. All three facilities had adopted the practice of attaching a butterfly[4] symbol to the door as a sign to all that the resident who lived in that room was dying. Notations in the Progress Notes commonly included that *palliative measures* had been started. There was no policy or procedure in any of the three facilities that specified the nature of palliative measures, nor does provincial legislation in Ontario provide detailed

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[4] The butterfly symbol was used to alert staff members that a resident was likely to die soon. The expectation was that additional care should be taken to show respect by avoiding noise, spending time with the resident, and attending to the comfort of the resident and family visitors.

direction about the standards for EOL care (Long-Term Care Homes Act, 2007). However, the Progress Notes implied that palliative measures included increased frequency of turning, oral care, attentiveness to family members, and increased attention to pain management.

In two instances, the documentation emphasized the expectation that death would occur within a few days of being deemed palliative. In one instance, a 98-year-old woman who lived with chronic obstructive lung disease and congestive heart failure who had declined over a period of 7 years in the LTC facility then developed pneumonia. The physician’s note 10 days prior to her death indicated that she was “almost palliative.”

She was “deemed palliative” and began receiving morphine on the day of her death.

In the second instance, an 89-year-old woman who had fractured her hip returned from hospital where she had developed a Methicillin Resistant Staphylococcus Aureaus infection, bloody stools, and anemia. Although she had been declined treatment for her anemia in hospital “due to her overall condition,” the chart indicated that the LTC facility physician and her son agreed that “palliative measures should not be started as she is not palliative at this point.” She died 11 days later.

Although not common, several instances were noted in which residents reported having seen, or were heard calling out to deceased loved ones. These behaviours were considered unusual and ominous, as these residents were thought to be cognitively well and not prone to hallucinations or altered perceptions. In contrast, no notes were found that suggested residents, family members, or staff had nearing death awareness expressed as premonitions, or could foretell the time of residents' deaths.

Chart review summary. A profile of decedents was created following an audit of the charts of 182 residents who died in three LTC facilities over a 12 month period. Deaths were considered to have occurred in advanced old-age if the resident was 85 years of age or older at her/his death. Two thirds of the deaths occurred in advanced old-age. Death in advanced old-age was more common for women and widowed individuals. Death was more common in the LTC facility as opposed to in hospital, in keeping with the advance directives that were present for almost all residents at the time of their death.

Documented awareness of impending death was rare before the last week of life. This was so despite that death was commonly attributed to one or more causes that were of a chronic, progressive nature, and often in advanced old-age. A marked change in the condition triggered a change in care. It was commonly documented that the resident had been "deemed" palliative by the physician within 1 to 3 days of death. Residents typically remained in bed after this designation, and "palliative measures" were said to have begun. Notes indicated that palliative measures included the administration of morphine and an anticholinergic medication, oral care, increased frequency of repositioning, communications with family members, and attempts to have someone sit with the resident.

Comments concerning residents' expressed readiness and/or wish to die were common. There was little to indicate how care providers regarded or responded to residents’ verbalizations about impending death.

Ethnographic Findings

In this section, the findings of the ethnographic stage of this research study are presented as they relate to the two key questions: (a) Is an awareness of impending death experienced by any or all participants in LTC; and (b) How does LTC culture influence awareness of impending death, and living with that awareness for participants (residents, family members, and staff members)? The findings are reported in relation to the themes that emerged through an iterative process of comparing, questioning, and grouping the data as described in Chapter Three. Two themes emerged for question one. Four themes emerged for question two. Although each question and theme is addressed separately in the paragraphs that follow, the questions and themes are reflexively inter-related.

Question one: Is an awareness of impending death experienced by any or all participants in LTC? As indicated, two themes, generalized awareness and clinical awareness, were identified in answer to question one. The data that led to the two themes are presented below.

Theme one: Generalized awareness. Awareness of impending death was expressed by all interview participants as an unavoidable reality for all human beings. Two administrators observed that: “The truth is we’re all palliative, so what way would you like to see yourself die?” and “Its part of life you know – you’re born, you live, you die.”

Personal support workers (PSWs) shared this same understanding as demonstrated in the following quotations from two long-time workers in LTC facilities: “Our people are at the last, right? Because this is the last stage of their life and a lot of them know that”; and “I guess you could say, in a way, really almost no one goes home from here – so in that sense they are all dying.”

Family members also reported their awareness of the inevitability of death, not as an immediately imminent event for their loved one, but as a reasonable and unavoidable fact of life: “What can you expect at 92 years? We didn’t think ‘Oh yeah, Mom is in LTC now so she’ll be dead soon,’ but I don’t think she’s going to live forever either – so in that way I wouldn’t be surprised – no.”

Some residents clearly articulated that they were aware of their mortality: “Everybody does it [dies], so it’s no big deal”; “I know I’m going to die someday – not soon I don’t think, but I know it will come to me;” and “I came here because I figured under the circumstances it would be a good place to live. I’ll go out sometime too, but not under my own power. I’m going to die here. People ought to realize when they come here – this is it.”

While none of the resident interviewees believed their death was immediately imminent, some realized that they could be dying at almost any time: “Well, I’m 85 years old this past March – so really we’re all on borrowed time here. Sometimes its really fast – like Emma (pseudonym) who sat at my table – she was bright as can be in the evening and then she has a massive stroke and never came out of it – it was just like that – so that’s what I mean – you don’t know, we just don’t know.”

Another resident mused about the equal possibilities of living another 10 years to reach 100 years of age, or “being gone tomorrow.” He concluded that “you never know; it’s a mystery at my age.” Another, who had reached the same conclusion, added that he had no need to think about death as he had lived the best life he could, and thinking about it would not change anything.

These exemplars suggest a generalized, philosophical awareness of human mortality, rather than an awareness of an immediate and personal event or process. Participants clearly acknowledged the potential for dying and death as part of reality for all human beings, and most particularly for those who were already very old. From this perspective, death in LTC facilities is always impending. However, in visits to the LTC facilities on 131 days to review records, observe, and interview; it was rare to hear that any particular resident was actually dying. Typical responses from Directors of Care and staff members to the question,” Is anyone here dying?” were: “Not today, but you should have been here a couple of days ago – we lost Mrs. S”; and “No, I wouldn’t say so, but T. soon will be palliative at the rate she is going.” These quotations suggest a second layer of awareness of impending death that is less philosophical and inclusive, but instead, more clinical and restrictive.

Theme Two: Clinical awareness. Clinical awareness of impending death was acknowledged when changes in a resident’s health status suggested that death was likely within a few days. Many staff members spoke about the importance of knowing residents over considerable time for noticing a turn in their condition. The exemplars below illustrate a strong belief among staff in LTC facilities of a finely tuned awareness, facilitated by close and ongoing relationships: “We know the little norms of people. We pick up on all the very small signals [because we have] very close relationships with these people” (Registered Practical Nurse); and “You know when something isn’t right – like Mrs. J’s just not herself” (PSW).

Staff members also recognized that daily contact with residents could sometimes make it more difficult to recognize gradual decline. In these cases, occasional visitors might be more sensitive to incremental changes. One Director of Care noted that: “I don’t get reports about people unless there’s a significant change – when its gradual maybe you don’t see it until all of a sudden you say ‘Oh my goodness!’ – then you wonder, when did that happen?” A Registered Practical Nurse (RPN) noted that when family members do not visit frequently, they may be surprised by the extent of decline between visits.

There was wide agreement among interviewed participants about the clinical evidence predictive of death. Participants spoke about a range of observations from early or potential signs to later and more certain indicators of impending death.

Early signs of impending death included:

- Social withdrawal or declining participation in social activities;
- Less zest for life, giving up, or letting go;
- Disinterest in or reduced intake of food and/or fluids;
- Increased time spent in bed and/or decreased mobility; and
- Speaking or dreaming of dead friends or family members.

Staff members noted these observations as ominous, but not necessarily as those that should be understood as indicators of immediately impending death. All had witnessed residents who had rallied when death had seemed certain. This experience is portrayed in the following quotations of staff members: “Sometimes it surprises you and the next day they rally back and seem to be back to themselves again - I think wow, what happened there?” (Director of Care); “We see many people cheat death. We think they’re close to that time, but then they bounce back” (Administrator); and “You see them rally, and they go back to their previous level of functioning, and I would have thought, you know, that was it – but they rallied – we can’t be sure, but I always say, this could be it, you never know” (Activities Director).

As portrayed in the following quotations of staff members, there was reluctance to consider a resident to be dying if there was any remaining possibility of a rally: “You never want to be the person who gives up on somebody” (RN); “We have some staff getting them up and dressed. They are doing everything as normal right up until they are into Cheyne-Stoking[5]. That’s where they struggle with what is active palliation” (RN); and “Sometimes I think we are too quick with palliative because I’ve seen people on palliative come back and they were here the next year” (PSW). Consequently, residents were typically not considered to be dying until changes were very advanced, and had persisted long enough that death was certain.

The degree of certainty necessary for administrative and clinical staff members to be comfortable in acknowledging impending death was not possible

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[5] Cheyne-Stoking refers to a pattern of breathing typically seen very close to death.

until within the last week or two prior to the death. Commonly, it was only within a few days that residents were deemed palliative: “I suppose this one lady, maybe you could say she was dying for 2 years – but I don’t call her palliative – when I say palliative I mean in the next week, actively dying” (RN); “The staff on the floor has to recognize when the time is right. We wait until they’re true end-of-life, within hours, and if we’re lucky we get days” (Director of Care); and “When the butterfly goes up many times I think, oh my, they have maybe a day. It depends on the staff” (RN).

Staff members were well aware of the later signs that death was nigh. The signs were:

- Changes in breathing patterns;
- Decreased level of consciousness;
- Abnormal body temperature; and
- Mottling.

When these signs were present, staff members acknowledged the imminence of death and the routines of care changed.

Family members expressed varying levels of clinical awareness of impending death, depending largely on their previous experience with dying. Some family members noticed the changes and intuited their significance: “Dad died in March and I guess it was at Christmas I just got the realization that this was going to be our last Christmas. The staff didn’t tell us – we just sort of got that impression. Then, I think it was about a week before he died, I heard someone mention the word palliative. I figured that meant a few days – in fact I couldn’t believe he had been hanging on that long.”

Other family members relied on staff members to interpret their observations and confirm their meaning: “I saw them swabbing her mouth. I knew she hadn’t been good - you know, going downhill for a while – but then I got the call in the morning. If I’d known I would have spent more time with her – been there you know- at the end. But if you don’t have the experience, how do you really know? They are the experts. I thought they would have told me.”

It was important to staff members that families acknowledge the certainty of death and complete an advance directive (such as the one in Appendix K) authorizing comfort care within the facility, without life prolonging interventions or transfer to hospital. This process was commonly referred to as “getting the family on board.” It was common for the advance directive to remain at a level three (i.e. opting for care in hospital) or two (i.e. opting for life sustaining interventions such as antibiotic therapy within the facility) until within a few days of the death. Staff members preferred that residents have a level one directive (i.e. comfort care within the facility) that was easily reconciled with standard palliative measures as outlined above, without further consultation with family members who were the substitute decision makers for residents.

Staff members commented that families often found it difficult to make the transition from level three to level two, or from level two to level one. They understood this reluctance to be indicative of denial of the realities of dying and death. They questioned the motivation of substitute decision makers who resisted making the change despite obvious decline in their loved one’s condition: “Often times I see someone whose quality of life is poor, and whose family - for what we perceive to be their own personal reasons or personal agenda – refusing, or insisting that they be sent to hospital. We just had one woman who I would say is 100% palliative - her Palliative Performance Scale was 20% - and we had the conversation, but her family only changed the advance directive from four to three - it's just because the family is in denial" (RPN).

Some staff members understood the challenge of changing advance directives differently: "Well, I don't mean to be crude or anything, but yes, it's I guess kinda like what you go through with a pet – you know having to decide if your cat, who's been just like one of the family, gets another chance - or is this it - kaput, you die - only I think it must be even harder if its your mother you're talking about - it's *her life* you're looking at - like wow, that's a big one to say, guess what, no more antibiotics for you" (PSW).

When the family was not on board, clinical staff members saw a "palliative conference" with the goals of assisting the family to accept the reality of impending death and agreeing to the initiation of palliative measures, as critical.

The palliative conference was not the only means by which families became aware of impending death. Some families were informally mentored in the development of awareness by watching other residents and their families, while others actively sought out information about their loved one's prognosis. The wife of one resident reported that she was learning about the approach of death by watching patterns on the units where her husband was a resident. She concluded that death is imminent when the resident is no longer brought to the dining room at meal time, and family members are present for more than their usual frequency of visits. Another woman whose father had died while a resident of LTC, and whose mother is currently a resident said: “You have to ask – I ask a lot of questions – if you don’t ask they will probably think you are not ready to hear it.”

Regardless of the mechanism, the late development of clinical awareness of impending death could interfere with getting the family on board, and could also interfere with multi- disciplinary care planning. One administrator described the problem: “The staff is just going around doing their jobs and then its like – oh whoa – and then it’s a scramble to get the doctor in, and the palliative meeting set up, and the sitters[6].”

Although the late development of clinical awareness of impending death can be problematic, some staff members were adamant that too much time between the recognition of impending death and the actual death was not only unnecessary, but detrimental and burdensome for the staff and family.

Directors of Care were asked to comment on two findings in the chart audit: (a) that for about half of decedents, no change in the level of support required had been noted in the last Quarterly Review prior to death; and (b) that in only one case had it been identified that the resident was terminally ill. Directors of Care in the participating facilities were surprised by these findings. They attributed them to the common practice of simply copying the previous Quarterly Review, which is part of an electronic document, and clicking on the appropriate

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[6] When family members are not available, “sitters”, often volunteers or staff members who stay after their shift has ended, sit at the bedside of dying residents so that they will not be alone as they die.

boxes if changes are required. They thought it would be easy in this process to miss a box, or leave it unchanged if the staff member was uncertain about the resident's current status as compared to at the previous review. Quarterly Reviews were completed by staff members from a variety of positions throughout the facilities, and sometimes by staff members who required a modified work assignment for health reasons. Under these circumstances, the resident might not have been well known to the staff member who completed the electronic form. Directors of Care believed that as funding was not influenced by the amount of EOL care that was required within the LTC facility, it was not a priority to document terminal decline for the purpose of reporting to the Ministry of Health and Long-Term Care. However, as funding was favourably impacted by the number of residents who were enrolled in rehabilitation programs, it was important to record data about the amount of rehabilitative service required by residents.

Summary. The ethnographic data revealed a layered awareness of impending death in LTC facilities. A generalized awareness was characterized by an understanding of human mortality and nearness to the end of a predictable life span. From this perspective, all LTC residents who were in advanced old-age were considered to be dying, regardless of their current clinical status. This generalized awareness was not prognostic, nor did it influence care practices. Alternatively, clinical awareness was linked to advanced signs of a progressive decline. Clinical awareness of impending death did foretell the actual death, usually within a few days, and was accompanied by changes in care priorities and routines.

Question two: How does LTC culture influence awareness of impending death, and living with that awareness for participants (residents, family members, and staff members)? Awareness of impending death in LTC facilities is embedded in, and influenced by the assumptions, beliefs, values, and contextual circumstances that manifest the culture of LTC. Four themes emerged from the ethnographic data as being important cultural influences on awareness of impending death in LTC facilities: (a) the belief that LTC facilities are for living; (b) the belief that no one should die alone; (c) the belief that no one should die in pain; and (d) the demands of care in LTC facilities, and the resources that are available to meet those demands. These four themes are described below. In this chapter, the themes are presented in the order in which they emerged from the interview data.

Theme one: The belief that long-term care is for living. While maintaining a generalized awareness of impending death, and developing clinical awareness in the presence of late signs of multi-system decline, interviewees from all three categories maintained that LTC facilities were places for living: “My biggest problem is getting Dad to understand that he’s come here to live, not to die” (Daughter of newly admitted 91-year-old man); “People don’t understand long-term care - it’s about care and living. It just happens that probably 95% of people do end up taking their last breath here” (Director of Care); and “Well I don’t plan to go before I have to – I like to keep busy – they always have something on for us to do. I don’t know if I will have time to die” (85-year-old female resident).

Staff and family members in particular seemed anxious to present contemporary living in LTC facilities as a contrast to the grim reputation of nursing homes in years gone by: “It’s an old stigma that this is a place to come to die – really it can be a new lease on life” (RPN); “I guess it’s the last place for a lot of our residents, but we don’t like to think of it that way. A lot of people still think we are just a warehouse here. They don’t know about all the changes – restorative care and activities – they don’t realize that. I think they should just come and see what’s changed” (RN); and “The generation of people that are coming in now still have that nursing home stigma in their minds from their parents and grandparents. We haven’t got over that yet” (Administrator).

Some participants worried that thinking of residents as dying might be considered disrespectful or neglectful. The following quotations illustrate the desire of staff members to avoid any appearance of ageism in the attribution of palliative status to residents who were among the oldest-old: “I think [families] struggle with saying ‘no, we don’t want them to go to hospital.’ They have a sense that they are abandoning their mother or father, and that they really should be doing everything they can, even though it’s futile” (Administrator); “Families just aren’t prepared to do less than - they feel obligated - they don’t want to be seen as abandoning - its their way of showing that they are still caring and interested” (RN); “When the decision is made to stop [antibiotics or fluids] its not because we’re giving up, it’s because it’s the best thing to do” (RN); “Why does age have to affect whether somebody’s going to – like, you know -having a do-not-resuscitate order - like just because he’s in his 90s - what’s the difference? We still should be treating him as a person” (PSW); and “I’d be offended if they thought our residents were dying. They may be old, but that shouldn’t make a difference” (RPN).

Some staff members reported active resistance to acknowledging the possibility of death. One PSW reported that when residents told her that they were dying, she usually tried to distract them by changing the topic or joking: “I just say, ’Wait ‘till you get a cup of coffee, that’ll perk you up,’ or I tell them they will likely outlive me so they shouldn’t get all hasty.” Another PSW was adamant that her job was not to provide palliative care because the focus was supposed to be on living. In one of the LTC facilities in this research study, members of both the Residents Council[7] and the Family Council had agreed that there should be sections about preparing advanced directives, funeral planning, and EOL care in a new handbook for residents and families. However, staff members on the Handbook Committee had rejected the idea, claiming that the topics were too sensitive to include in a handbook.

Neither administrative nor clinical staff members thought it was desirable to think of LTC facilities as centres of excellence for EOL care, even though approximately 1/3 of their residents died each year. While several staff members agreed that a lot of palliative care was provided in the nursing home, others objected to calling their work palliative care. They shared a concern that it would not be good marketing to be too clear in presenting the realities of dying and death

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[7] Resident Councils within LTC facilities have been organized to provide a forum for residents to discuss their concerns and participate in advocacy to improve the quality of life in LTC facilities.

in LTC facilities: “Well, I don’t think that [being a centre of excellence for EOL care of the elderly] would sound too good now would it – if we said that in our marketing – I can imagine that families wouldn’t be too excited about that – oh yeah, we’re taking Dad to die” (Director of Care).

Nevertheless, despite the strong preference to characterize LTC facilities as places to live rather than to die, participants believed that residents were well cared for in the nursing home when they were finally deemed palliative. Good EOL care enabled residents to die comfortably in the presence of family members and at home in the LTC facility. These beliefs are explored in detail in the following sections.

Theme two: The belief that no one should die alone. Family members and staff care providers routinely voiced the significance of being present with dying residents. For staff members it was a compelling aspect of duty, honouring the dignity of residents, and justifying their trust: “I’d like to think that right up to the very last moment they’re going to know that someone is there with them, and they won’t be afraid” (RPN); “So this one man, he looked like he wasn’t going to be here by suppertime and the RN called the family – but like, where were they? I’m thinking, I’m supposed to be in the dining room helping, but they aren’t screaming for me out there, so I stayed with him - it was about twenty to twelve, and he passed away about twenty to one. The RN thanked me. I said he deserved to have company” (PSW); “We still have staff getting them up and dressed and taking them to the dining room, or dropping them off at a special event when we know someone’s actively palliative - they don’t want them to be by themselves, don’t want them to be alone” (Director of Care); and “If I’d known I would have been there at the end. That’s always bothered me about my mother’s death. I want to know in time for my husband. I want to be able to call our children” (Spouse). This last comment emphasizes the importance for family members of timely clinical awareness of impending death in facilitating closure. However, staff members were aware that it can be difficult for family members to fulfill the duty of being present when “true dying” takes more than a few days: “[If dying takes any longer than] a week it’s too hard – because you know, they may want to sit there around the clock” (Administrator); “You see families that don’t make it on time. This gentleman that just died, his son had been with him all the time except when he died at midnight, and I know without even talking to him, that he’s going to have that regret that he wasn’t there” (RN); and “The family would rather be there at the time of death if at all possible. But I find that actually it is very difficult, very challenging for families to achieve” (RN).

In the absence of family members to keep a vigil, staff members attempted to be present by redistributing their work load to allow someone to be present with dying residents: “One time we had this lady whose family lived out of town, and I knew they were coming, and we were so busy on the floor, but she was alone and it wasn’t right. I wanted to be with her, so I spoke up, and after that they changed it. So now a staff member would be designated [to sit with the dying resident] and the other girls would pick up the slack. I was actually kind of proud that I had made that difference” (PSW).

Staff members were concerned that residents who were transferred to a local hospital might be left waiting for attention in the hallway of an overcrowded emergency department, and die there without anyone who really knew them. As one PSW said, “It would be my worst nightmare to think they ended up dying all alone up at the hospital when we could have been with them right here.” A family member echoed a similar sentiment: “I don’t know, you know, I guess the hospital is supposed to be where the best care is, but I kind of think I would rather have Mom here where all the girls are almost like family to her.”

The development of a clinical awareness of impending death enabled staff members to make the changes in the routines of care and distribution of work in order to orchestrate an accompanied death. In the absence of additional funding for staffing, this willingness to “pull out all the stops” and “go the extra mile” testifies to the strength of the belief that no one should die alone: “You don’t put a price tag on it - if there has to be someone to sit with them, you don’t count the cost. It’s the one time when people rally around - will go far, far beyond what they would normally do” (Director of Care).

Theme three: The belief that no one should die in pain. Staff members and family members expressed the belief that residents should not die in pain. Facilitating comfort was understood to be a compelling duty: “We manage pain very well here. We get on top of it quickly. No body ever wants to think that somebody died in pain. That would be like thinking your child was going hungry” (Director of Care); “At that stage they can’t tell us, so we have to assume it’s pain if they are restlessness. We try morphine and see what happens. It is about comfort. We have to keep them comfortable” (RN); and

"People are usually put on morphine at the end - one of those little shunt things (subcutaneous lock for intravenous administration of medication). So I know the nurses I can get to do things, and so I just say, hey, Mrs. So-and-So is in pain, she needs her meds" (PSW). For this PSW, the presence of the subcutaneous lock had become a signal to expect death and to change the organization of her work: "When you come on your shift and you see [the subcutaneous lock], you know you gotta be in there doing palliative measures" (PSW).

It also became apparent throughout the interviews that although there was no formalized palliative protocol in any of the three participating LTC facilities, palliative measures included pharmacological interventions that required a physician's order, intensification of nursing care facilitated by redistribution of duties among an already busy staff, and closer liaison with family members. The goal of palliative measures was to facilitate comfort and avoid suffering. At this late stage in the trajectory toward death, palliative measures included:

- Administration of morphine;
- Administration of anticholinergic medication;
- Discontinuation of medications not related to ensuring comfort;
- Increased frequency of oral care;
- Increased attention to turning and repositioning;
- Decreased concern about maintaining oral intake;
- Communication with family members to negotiate care directives consistent with comfort care within the LTC facility;
- Increased attentiveness to the needs of family if they are present;

- More frequent ”checking in” on the resident;
- Decreased concern to get the resident up out of bed;
- Arranging “palliative sitters” (staff or lay volunteers) if family members were not able to keep a vigil.

These changes in the approach to care and distribution of tasks required timely clinical awareness of impending death. Otherwise, there was a sense that the death was not as good as it could have been: “You just scurry around and hope it’s all in place in time” (Director of Care); and “When I started here they told me they did really good palliative care, but I saw it differently. I mean when the butterfly finally goes up I think they get everything they need, but it could have been picked up days before and we could have started measures earlier. I know they are old and it’s OK to go, but they could have gone more comfortably” (RN).

One nurse-manager, who defined palliative status as beginning when the advanced directive was changed to a level 1 (as described in Appendix K), noted that her staff tended to perceive palliative status as requiring that all of the measures listed above be instituted for every resident as soon as she/he was deemed palliative. While some of the measures seemed appropriate for a given resident, it was not until all measures were appropriate that this staff member was comfortable in acknowledging impending death and having a resident deemed palliative. This belief acted as a barrier to planning for a palliative approach to care: “I notice a large hesitance on the part of my RNs to have the conversation with families to go from a level 2 to a level 1 in the care directives because they feel that the minute they do that, everyone - you know, will stop caring for them.

So they hesitate. But even so, actually a palliative patient gets a tremendous amount of care - probably more than a patient who is up. I think their hesitance is in the change, and realizing that - its going to be like this. It’s never going to be the way it used to be for this person” (Director of Care). The circularity of this argument is significant: a resident cannot be considered to be dying unless her/his advance directive is at level 1 and a resident should not have a level 1 care directive unless she/he is dying.

Theme four: The demands of care and available resources. As reported in Chapter Two, the ordinary activities and conditions in a setting take on moral tone and meaning that are the culture of that place (Kleinman & Benson, 2006). In LTC facilities, the demands of care and the resources available to meet those demands are significant elements of the contextual circumstances that are part of their culture.

Long-time staff members at the study sites described changes over their years of employment that challenged their capacity to provide the quality of nursing care they desired to provide on a daily basis. Among the changes were:

- The admission of older, more frail residents;
- A shorter duration of stay between admission and death;
- A reduction in number of staff (see Table 3) and also the qualifications of nursing staff;
- A loss of resources such as a designated room for the provision of palliative care for residents and families; and
- The discontinuation of services or programs (such as the provision of

> palliative sitters) that had relied on extra service provided by staff who volunteered after their regular hours of work.

With limited resources, staff members sought to provide palliative measures for residents for whom impending death is acknowledged, in addition to usual care for residents who were not considered to be dying.

Table 3

Current Staff-to-Resident Ratios on Weekdays *

Shift/staff	**Days**	**Evenings**	**Nights**
RN **	1:60-120	1:80-200	1:175-260
RPN	1:35-40	1:30-35	1:50-80
PSW	1: 10-15 ***	1: 10-15 ***	1:50

* varies with size of facility

** generally 1 RN per facility at night regardless of number of residents

*** additional part-time staff assist during mealtimes

The impact of low staff-to-resident ratios on quality of care was noted by family members who were interviewed: “Well, I can see that Mom is going down hill, but what’s really hard is that she can’t get to the bathroom on her own anymore, and there isn’t enough staff to get her there on time when she rings. So she wets herself, and that really is upsetting for her. I tell her that she can just let it go because they have her in a brief now. But she can’t bear that indignity. Its hurts more to hear her say that, than to think she’ll be gone some day” (Daughter); and “My biggest problem is finding the nurse to talk to. Sometimes I wonder if anyone works there because you can look and look and never find a nurse. I see some PSWs here and there, but they are busy – and really, I don’t expect them to tell me about medications or the more technical things about Mom. It’s just a shame they can’t have more staff there” (Son).

Registered Nurses also expressed their concerns about the consequences of staffing patterns for the quality of care: “I mean, we do a darned good job with what we’ve got. Once they are deemed palliative they get everything. But that’s still often not a full assessment. Do they need a breakthrough? Are the meds working? The RPNs are so tied up on the floor they often don’t get back to do the assessment” (RN); and “I really worry about the devolution of work to RPNs and PSWs because where’s the critical thinking - you know, the timely assessment and evaluation. I saw in a chart that this resident had had nausea for 2 weeks and the Gravol® had been given but no one thought ‘this isn’t working’ – no one did anything about it – they just said she’s had all her meds.”

It was common to hear staff members and family members speak of the intensification of care in the last few days prior to death. Sustaining “ultra attentiveness” particularly if more than one resident was thought to be dying at the same time, was difficult for staff members. One RPN said: “At first you concentrate on making sure they aren’t suffering, and you don’t worry about meals, but after a while, time goes on, and you begin to think maybe there is more time than you thought, then it kind of wears off and you go back to usual.”

In addition to the challenges of providing adequate care (given the staff-to-resident ratios) staff interviewees noted the impact of levels of staffing on the availability of educational opportunities: “If you want to take one off for education, you’re leaving 2 staff with 64, and 70% of people in LTC homes are 2-person lifts. So one person wants to go on the toilet, you’ve got the other 31 residents with nobody out on the floor to take care of them. So, it’s really a low, low ratio. When the RNs are there they’re covering a number of floors. The ratios are just far too low. And that’s why education becomes impossible - and there’s no support for them - and why they feel overworked - they are” (Manager); and “You know they send 1 or 2 people to the palliative education days but then there isn’t any way of getting everybody else on board when they come back. So it just kind of fades away after a while. So you have to wonder, what’s the point” (RN).

Family members and residents reported considerable satisfaction with the EOL care that they had observed, despite the workload challenges described by staff members. They understood the extra efforts of staff members in the last days of their loved ones’ lives as evidence that they had not been abandoned. For current residents, it was a source of reassurance that they too would be well cared for during their own inevitable dying:

“When I think about my own future – and you know my time will come, I know I will have good people looking after me. I don’t worry about that” (Resident); “They take real good care of you here. I saw that with my wife. She died here just a couple of months ago, so I don’t have anything to worry about” (Resident); “Well, they were always caring but I would say near the end they went from a caring mode to a super caring mode – hyper-attentive I would say. We couldn’t have asked for more” (Daughter of a current resident and a decedent).

Ethnographic Summary. The ethnographic data revealed four themes.

Three were strongly held beliefs. The fourth theme concerned contextual factors within the LTC facilities. The three strongly held beliefs that influenced the development of awareness of impending death were: (a) LTC facilities are places for living; (b) no one should die alone, and (c) no should die in pain. Low staff-to-resident ratios and few registered staff compared to unregulated and minimally educated staff were significant contextual factors in the culture of LTC.

Chapter Summary

The findings from a two-stage mixed methods study have been presented in this chapter. The findings for the first stage were derived from a review of selected socio-demographic variables and evidence of awareness of impending death as they were documented in the charts of decedents. These findings described the population that died in the three LTC facilities that participated in this research study. Among the 182 decedents, two thirds died in advanced old-age. Death in advanced old-age was more common for women and widowed individuals than for men and married individuals. Death was more common in the LTC facility (90.1%) than in a hospital. This location of death was in keeping with advance directives which were present for almost all residents on the day of their death. Residents were commonly “deemed palliative” after the staff noticed a marked decline in the resident’s condition and called the physician, usually 1 to 3 days before the death. Residents typically remained in bed from that time onward, and “palliative measures” were said to have begun.

The ethnographic findings in the second stage of this research study revealed evidence about the nature of awareness of impending death in LTC facilities (two themes), and about the assumptions, beliefs, values, and contextual circumstances that are among the cultural influences on awareness in LTC facilities (four themes). A generalized awareness of impending death was characterized by an understanding of human mortality and nearness to the end of a predictable life span. This generalized awareness was not prognostic, nor did it influence care practices. Alternatively, clinical awareness was linked to advanced signs of progressive decline. Clinical awareness of impending death normally did foretell the actual death, usually within hours or a few days. Clinical awareness of impending death was accompanied by changes in care priorities and routines to facilitate dying in a way that was consistent with strongly held beliefs about the nature of an acceptable death in LTC facilities.

The beliefs and contextual circumstances that influenced awareness of impending death are considered to be elements of the culture of LTC. Three beliefs were pervasive: (a) LTC facilities are places for living, not for dying; (b) no one should die alone; and (c) no should die in pain. The reality of scant human resources, as manifest in low staff-to-resident ratios and few Registered Nursing staff compared to unregulated and minimally educated clinical staff members, was a significant contextual factor in the culture of LTC.

Chapter Five – Discussion

This chapter is divided into four sections: (a) a summary of interview participants' narratives about impending death; (b) a review of the key findings; (c) discussion related to research question one: Is awareness of impending death experienced by any or all participants in the culture of LTC?; and (d) discussion related to question two: How does LTC culture influence awareness of impending death and living with that awareness for participants (residents, family members ad staff members)?

In this research study, using Schien's (1985 definition of culture as described in Chapter Two, the focus was to develop an understanding of the assumptions, beliefs, values, and contextual factors within the culture of LTC facilities that influence the development of awareness of impending death. The culturally approved account of a particular phenomenon is expressed in a related discourse. Small, Froggatt, and Downs (2007) defined discourse as "a systematized structure of significance, supported by and supporting social power and narrative" (p. 6). The findings of this research study suggest that awareness of impending death among the oldest-old in LTC facilities develops at the intersection of the discourse of LTC facilities as places for living, and the discourses of dying and death that focus on orchestrating a good death. This conclusion will be discussed later in this chapter as it relates to the research questions. That discussion is prefaced by the following summary of interview participants' narratives about impending death as compared to the findings in previous reports of research.

A Summary of Interview Participants' Narratives about Impending Death

In the ethnographic stage of the study, residents of LTC facilities, family members of residents, and staff members spoke about impending death as an aspect of their respective realities. Constant comparative analysis of their words, in conjunction with observations of the day-to-day activities in the LTC facilities, and examination of artifacts within the facilities revealed the cultural influences on awareness of impending death. All three participant groups contributed to the resulting description of the significant influences on the development of awareness of impending death within the culture of LTC facilities that are described in detail in Chapter Four. The brief composites below encapsulate a generalized account of the perspectives that were shared among interview participants in relation to their integration of the reality of impending death within LTC culture.

Residents acknowledged their potential to die at virtually any time because they were very old. They faced this possibility matter-of-factly and reported that they did not dwell on dying and death. Like the oldest-old in Hinck's (2007) and Timomen and O'Dwyer's (2009) studies, resident participants in this research study focused on making the best of their current circumstances despite the losses that marked their advanced age and increasing dependency. Much like participants in Munn et al.'s (2008) and Mathie et al.'s (2011) research, residents in this study acknowledged dying and death as both common and normal at their age. They faced the reality of dying with confidence that they would be well cared for as they had witnessed the attentiveness of staff to other dying residents in their last days of life.

Staff members relied on clinical observations to identify the potential for dying. Risk assessment for mortality using tools such as those that have been validated by Hirdes et al. (2003) and Porock et al. (2005) were not used in any of the three participating LTC facilities. Staff members were reluctant to acknowledge dying as an inherent aspect of the culture of LTC facilities, preferring to focus on living until hours or a few days before death. This finding is consistent with Bern-Klug's (2004, 2006, 2009) and Veerbeek et al.'s (2008) findings that the possibility of death for nursing home residents was acknowledged very close to the time of actual death. Bern-Klug was concerned that failure to recognize the possibility of dying earlier in the trajectory toward death could deprive residents and families of appropriate and timely EOL care. In the three LTC facilities where data were collected for this research study, it was documented that palliative measures were typically instituted in the last hours or a few days before death. However, most staff participants in this research, as in Hov, Athlin and Hedelin's (2009), took pride in their ability to provide comfort and compassionate presence for residents and families when the reality of imminent death could not be avoided.

Only a few comments from staff participants suggested the possibility that care, particularly the management of pain and other symptoms, could have been improved prior to the resident having been deemed palliative. Thus, they generally believed that they had contributed to making dying and death as good as it could be with the resources available to them.

Family members focused on their need to be aware of the approach of death in order to make appropriate plans for visitations, and to be present through the last hours of life of their loved one. Bern-Klug (2006) also found that the need of families to make plans could be an important trigger for conversations about *possible dying.* Some family members in this research study acknowledged their frustration with the minimal human resources available in the LTC facilities to provide the usual everyday care for residents who were not considered to be dying. Like participants in other studies (Munn et al., 2008; Munn & Zimmerman, 2006; Shield et al., 2010), family members in this study identified their central role as advocates for ensuring that their loved one received appropriate care. However, they expressed great satisfaction with caring practices when death was near. They had witnessed that their loved one had become the centre of attention and had been treated with special care in their last few days or hours of life. Consequently, the death was seen as having been satisfactory and acceptable, regardless of any concerns about quality of life before their loved was recognized to be dying. Parker (2011) described the identity of the dying self as one that becomes available to LTC residents who are understood to be dying. Perhaps these family members had observed the changes that were required in a newly crafted relationship between care provider and the dying resident. The dichotomization of living and dying will be discussed in a later section with respect to the implications of the findings of this research study for policy and practice in LTC facilities.

A Review of the Key Findings of This Research Study

The themes that were identified in Chapter Four are regrouped in this chapter to reflect their influence on awareness of impending death within LTC culture. The relationships among themes are illustrated in Figure 1. In brief, the belief that LTC facilities are for living, not for dying; and the scarcity of resources to meet the high level of need for the ongoing supportive care of residents, were barriers to acknowledging impending death. The beliefs that no one should die alone, or in pain provided bridges to acknowledging impending death. Acknowledgement of impending death justified the modification of care routines for a short period during the process of active dying despite the scarcity of resources. These themes concerning dying and death, and the practices they support, are part of the culture of LTC facilities and were embedded in residents', family members', and staff members' perspectives on impending death as described in Chapter Four.

Discussion related to Question One: Is awareness of impending death experienced by any or all participants in LTC?

Participants in this research study expressed a generalized awareness that all residents of LTC facilities who were among the oldest-old could be considered to be dying by virtue of their advanced old-age. However, contrary to the recommended best practices for the initiation of a palliative approach to care (Canadian Hospice Palliative Care Association, n. d.); it was considered inappropriate and unhelpful to acknowledge impending death until the prognosis was undeniably short and certain. Rather than beginning well in advance of the event of death, the acknowledged living-dying interval was typically only a few hours, or a day or two. The following consideration of two existing palliative care discourses will help to explain the late adoption of a palliative approach to care for a population that could be considered to be near the end of life from the time of admission to the LTC facility.

Discourses about dying and death. Within the developed world, death is increasingly an experience of the oldest-old (Northcott & Wilson, 2008). Amid the therapeutic interventions made possible by modern biomedical science, the notion of accepting death may seem unnecessary, if not uncaring or negligent (Callahan, 2005; Kaufman et al., 2004). Nevertheless, with aging comes the certainty that less time remains for living. Questions concerning the meaning of being, the possibility of ceasing to be, and the anxiety that is commonly associated with the prospect of death remain open, compelling, and repelling altogether. As the only perspective that can be brought to these questions is the perspective of the living, the struggle to understand death is complicated by the difficulty of its representation. Krell (1978), speaking of Heidegger’s hermeneutic of Dasein, and recognizing the ineffability of death and interpretation, identified the crucial problem as that of “letting death be” (p. 247). Letting death be is no small challenge given human curiosity and the Western appetite for scientific understanding and control. Two discourses have developed in attempts to master the matter of mortality in modern society. The first rejects death. The second faces death, but only when avoiding it is not possible. These two discourses, and their contribution to understanding awareness of impending death in LTC facilities, are discussed in the next section of this report.

Rejecting death. Advances in healthcare science and public health in modern societies have lead to a remarkable extension in life expectancy over the last century (Northcott & Wilson, 2008). The gains that have been made are commonly represented as victories over enemy diseases, or successes in risk management (Twycross, 2002). Each death has a cause, and each cause can be overcome. The aging of modern societies around the world can be understood as evidence of the clever and relentless work of scientist-warrior-strategists who oppose and conquer disease. From this perspective, death is represented as unfortunate, unnecessary, tragic, a defeat, and a problem to be solved.

For those who face an untimely or premature death, the search for a cure to mortality is, no doubt, compelling. When dying is represented as a problem, sustaining life is the solution. Ultimately, this modern view of mortality implies that death may not have to be inevitable for human beings. Questions related to dwelling in our mortality (Burch, 1986) fade in the glow of our anticipated success in avoiding death. Objectification in scientific research and the depersonalization involved in some radical medical interventions are rationalized by the possibility of an extended future. Yet, Taylor (1991) suggested that openness to being treated as raw materials in scientific explorations, or as the instruments of our projects, is among the malaises of modern society. Furthermore, Burch (1986) warned that pride in accomplishments may compromise the wise consideration of the significance and meaning of the feats that are possible. These cautions about the implications of doing everything that is possible or letting death be, are at the crux of the ethical considerations about planning for the most appropriate care of individuals in advanced old-age. Care planning near the end of life, as it was represented in the findings of this research study, is discussed in the next section.

Care planning near the end of life. In this research study, over 96% of the deceased residents in both younger and older age groups had a completed advance directive at the last Quarterly Review prior to their death. It was common for the advance directive to remain at a level three (i.e. opting for care in hospital) or two (i.e. opting for life sustaining interventions such as antibiotic therapy within the facility) until within a few days of the death. Perhaps this pattern reflects a choice to reject death as long as possible.

Family members in this research study, like those in Shield et al.'s (2010) study, took their responsibility as advocates very seriously. Shield et al. found that end-of-life advocacy was facilitated when family members had time to build trust and prepare for death. Similarly, Lopez (2009) found that family decision-makers were motivated by the desire to do what was best despite the uncertainty of the situation, and conflict between the values of protecting life and avoiding suffering. Family members in this study were similarly concerned about doing what was best, but uncertain about when pursuing further assessment and interventions would no longer be the most caring thing to do. Hence, maintaining the advance directive at a level 2 or level 3 until death is inevitable within a few days or hours may reflect the need to be more certain of the possibilities, rather than denial of an obvious reality. From this perspective, it may be easier to understand and accept that family advocates delay turning toward death until it is unquestionably clear that prolonging life is no longer the loving, caring thing to do. Often, a family member's account of this decision point was accompanied by comments such as, "We didn't want him to have to suffer any longer."

In this research study, the frequencies of completion of advance directives, transfers to hospital, and death in hospital differed as compared to those in previously published reports (Daaleman et al., 2009). This population of LTC decedents had relatively high rates of identification of power of attorney for health care (more than 96%), and completed advance directives at the last Quarterly Review prior to death (about 96%). There were relatively low rates of hospital transfers in the last month of life (22.6%), and deaths in hospital (8.1%) among those aged 85 years or older. These patterns are consistent with the goal within the health care system reduce the number of inappropriate hospitalizations of nursing home residents at the end of life (Ahearn, Jackson, McIlmoyle, & Weatherburn, 2010; Central East Local Health Integration Network, 2009; Menec, Nowicki, Blandford, & Veselyuk, 2009; National Health Service, 2009).

As noted in the findings outlined in Chapter Four, a local influence on the location of death in the current research study is the crowded emergency department at the hospital in the area where the study sites are located. Staff members were concerned that residents who were transferred to hospital for any reason would likely spend hours, if not days, on a gurney in a busy hallway in the emergency department. They believed that residents were likely to be "shipped" back to the LTC facility having received minimal assessment and treatment, or would die alone in a busy hallway. They considered hospitalization as an abandonment of their LTC residents as compared to remaining to be cared for in the LTC facility. Consequently, in consultations with residents and families, staff members emphasized the advantages of remaining “at home” in the LTC facility in the presence of familiar caregivers. Decisions to forego hospitalization may suggest the beginning of a turn toward facing death.

Turning toward death – the palliative discourse. In contrast to the death-rejecting discourse, the palliative discourse turns toward death. This discourse recognizes the priorities of comfort and integrity for individuals and their families when life is perceived as finite, and proximity to death is acknowledged (Canadian Hospice Palliative Care Association, n. d.; Widder & Glawischnig-Goschnik, 2002). A good death, marked by the management of pain and other symptoms, and the negotiation of psychosocial, emotional and spiritual challenges, is the measure of success of palliative care (Canadian Hospice Palliative/Care Association, n. d.).

Appropriate as the palliative discourse sounds with respect to dying in advanced old-age, it is uncommon for the oldest-old to benefit from it (Meier & Morrison, 1999; Murtagh et al., 2004). Typically, the individuals who are admitted to palliative care units or community-based palliative care programs are dying at a younger age than would otherwise have been expected, as a result of life-shortening diseases such as cancer or degenerative neurological conditions (Murtagh et al., 2004). Consequently, death is experienced as unnatural, untimely, and often as a tragedy; given unrealized personal potential and the impact of the impending loss on young family members. This representation of death is questionably appropriate for the oldest-old in LTC facilities, considering that they have already lived a life that is much longer than most, and experience a different constellation of causes of death than younger adults (Goldberg & Botero, 2008; Lunney et al., 2002; Lynn, 2005; Mitchell et al., 2009; O'Connor & Bullwinkel, 2009; Wilson & Cable-Williams, 2009). Residents and family members in this research communicated the belief that death could be expected in advanced old-age regardless of the presence of life threatening illness. From their perspective, advanced old-age was a common cause of death in LTC facilities.

Common causes of death in LTC. The following comments regarding common causes of death in this research are limited by their dependence on the completeness and accuracy of transcriptions from death certificates into a record book on the units where decedents had lived. Death certificates are also acknowledged to be imperfect, and limited in accuracy for the interpretation of the causes of death, particularly when there have been multiple co-morbidities. Nevertheless, the data concerning causes of death in Table 1 offer insights that are consistent with patterns that have been identified elsewhere concerning causes of death of the oldest-old, and thereby may be part of a larger epidemiological pattern (Goldberg & Botero, 2008; Lunney et al., 2002; Lynn, 2005; Mitchell et al., 2009; O'Connor & Bullwinkel, 2009; Wilson & Cable-Williams, 2009). The key findings related to causes of death in this study are:

- Dementia was the leading cause of death among the oldest-old and the second leading cause in the under 85 year-old age group;

- Pneumonia was the leading cause of death in the younger than 85 year-old group, and the seconding leading cause among the oldest-old;
- Myocardial infarction was the only acute cause of death in this study population, and only among decedents who were younger than 85 years;
- Cancer was not among the nine most common causes of death for either younger or older decedents;
- Multi-system failure was cited more than three times as often for the younger age group than the older group;
- Death was attributed to natural causes more than four times as often for the oldest-old than for the younger group.

Two implications of these findings are discussed below; (a) the influence of oncology on palliative care in LTC facilities, and (b) the attribution of death to natural causes.

Death in LTC facilities is likely to be due to chronic progressive diseases with the dwindling trajectory of dementia, or the trajectory of exacerbating chronic illness such as chronic congestive heart failure. The need for developments in palliative care appropriate for these trajectories has only recently been identified. As a result, it may still be common for a palliative approach more appropriate for cancer-related dying to be projected into LTC facilities (Albinsson & Strang, 2002), even though this study and others have found that cancer is not a common cause of death among residents of nursing homes.

In this research, a significant local influence on EOL care in the study sites was a regional palliative education and consultation service which includes a LTC initiative. This initiative is rooted in oncological palliative care. Interestingly, while very few deaths in the study sites were attributed to cancer, staff participants often spoke of cancer in the interviews. A registered nurse and palliative practice consultant who works in the program expressed that staff in LTC facilities needed much more knowledge about the end stage of various diseases such as pancreatic and ovarian cancers. However, the diseases that more typically contribute to death among residents of LTC facilities, such as dementias, pneumonia, and chronic pulmonary or cardiac diseases (see Table 1), were not identified as priorities for palliative education by this clinical leader.

One of the goals of the regional LTC palliative initiative is to institute the use of the Palliative Performance Scale (PPS) (Lau, Downing, Lesperance, Shaw, & Kuziemsky, 2006) and Edmonton Symptom Assess Scale (ESAS) (Capital Health Regional Palliative Care Program, 2010) in the region’s LTC facilities. Both tools are commonly used in palliative care units where cancers are common causes of death. The PPS is more commonly used as a prognostic tool with individuals who are already considered to be palliative (Lau et al., 2006). The PPS has not been validated in LTC facilities, or for residents with dementia who are likely to be dependant for care longer than those who die of cancer. The ESAS is a self-reporting tool used to assess a variety of symptoms and evaluate their management. The ESAS requires cognitive and verbal abilities, a problem in LTC facilities as these abilities are no longer intact for many of their residents, especially in the advanced stage of dementia.

Some registered nurses confessed to having difficulty in using the PPS and the ESAS, and in interpreting their results: “I’ve used the PPS in the community and its great to get an idea where you are going - and the ESAS too - but it’s a guess, and here it’s even a longer guess - so it’s great to have scales but I don’t know how appropriate they are for these people” (RN); and “I would say there is probably 25% of the population that would have a PPS of 30 [a score usually considered to be indicative of a short prognosis] or lower but they may have had that score for numerous years. We would not consider them particularly palliative or requiring EOL care with that score until there was a significant change - a sharp decline - because you see - well, most of these residents are already completely dependent for their activities of daily living” (RN).

Questions thus exist about the appropriateness of both the PPS and ESAS for use with residents of LTC facilities. Nevertheless, the introduction of these tools in LTC facilities is indicative of laudable efforts to improve EOL care in LTC facilities. However, failure to recognize the real nature of dying in LTC facilities can be an invisible barrier to the development of an appropriate palliative care philosophy, policies, and practices in nursing homes. Perhaps the maintenance of this barrier is a part of a pervasive desire within a death-avoiding Western world view to construct dying as part of a disease process that can be overcome. The alternative would be to accept dying as unavoidable, and the ultimate human reality.

Residents who participated in this research expressed that dying at their age was both expected and natural. Likewise, family members acknowledged that death would not be unexpected given the age of their loved ones. As illustrated in

Table 1, the proportion of deaths attributed to natural causes by attending physicians at the research sites was four times greater for decedents who were among the oldest-old than for those younger than 85 years. Dying “naturally” is often cited as a characteristic of a good or preferred death (Northcott & Wilson, 2008). Attributing death to natural causes may imply a belief that nothing should have been attempted to change the course of events. From this perspective, it would appear that death was considered to be more in keeping with the natural order, and therefore more acceptable, after the age of 84 years than for residents who are younger that 85 years. Perhaps the attribution of death to natural causes serves as a proxy for *death due to old-age* which is not a recognized cause of death in the International Classification of Diseases.

In EOL decision-making with the oldest-old and their powers of attorney for health care decision making, the question arises whether a decision to acknowledge and accept dying is allowing a natural, and perhaps preferred death, or reflecting ageist judgments about the value of the elderly individual and the desirability of sustaining her/his life. The line between appropriate consideration of the significance of age and ageist discrimination is not clear. For many family and staff members who participated in this research study, uncertainty about the acceptability of death was resolved by considering that no one was dying until death was unquestionably unavoidable and within a very short time. Hence, LTC facilities were understood to be for living, and as one administrator observed, “It just happens that 95% of our residents take their last breath here.”

In summary, both the death-rejecting discourse and the palliative discourse represent death as unfortunate, unnatural, and untimely; and if not avoidable, then at least manageable. Yet, for the oldest-old who approach death through natural senescence (Agich, 2003), death could be seen as natural, timely, and perhaps even the fulfillment of one’s humanity (Chapman, 2004). This perspective is not well articulated outside theological and religious literature. Instead, health science literature has privileged the death-rejecting and palliative discourses. As a result of the absence of an EOL discourse that is appropriate in the context of frailty and advanced old-age, the oldest-old are at risk of being “marginalized” (Hall, Stevens, & Meleis, 1994) as they live toward the end of life.

Marginalization of the oldest-old at the end of life. The finding that dying is commonly acknowledged very close to the time of death suggests the potential for the oldest-old who reside in LTC facilities to be marginalized (Hall et al., 1994) with respect to the timely initiation of palliative approach to care. It is important to understand the oldest-old as a population at risk of marginalization in order to undertake appropriate advocacy on their behalf. Hall et al. identified the peripheralization of those who differ from those at the centre of influence as a defining property of marginalization. For the oldest-old, especially for those who reside in LTC facilities, marginalization is not merely the result of being sidelined in social activities by waning energy, difficult mobility, or sensory impairments. Rather, it refers to a value-laden attitude toward one’s proper place in society (Hockley, 1990). Seniors in advanced old-age suffer twice in this regard: First, as seniors in Western societies that value youth; and second, as the oldest-old, who by virtue of age-related frailty and vulnerability, portray the realities of aging that are most feared by younger seniors (Agich, 2003). Thus the oldest-old are at risk of being marginalized by those who are not old, and by those who are old, but not yet in advanced old-age.

In this research study, the attempts of residents to talk about the possibility of dying were subject to the power of their care providers, who were younger, to censor or change the topic of conversation. Health care workers have been found to be most likely to set the agenda in conversations with LTC residents (Burgio et al., 2001; Jones & Wright, 2008; Scocco et al., 2006; Timonen & O'Dwyer, 2009; Wadensten, 2005; Wadensten, Conden, Wahlund, & Murray, 2007), and to avoid communications concerning dying and death (Bern-Klug, 2006; Forbes, 2001; Jones & Wright, 2008; Lloyd-Williams, Kennedy, Sixsmith, & Sixsmith, 2007).

Black and Rubenstein (2004) also reported that residents of LTC facilities were rarely asked about their experiences of loss, grief, and their approach to the end of life by nursing home staff. Furthermore, residents had concluded that it was best not to initiate such conversations with their caregivers in order to spare the caregivers from vicarious suffering. As their caregivers reported the belief that the elderly residents were not suffering, the residents had apparently kept their secret well. Secrecy is another of the properties of marginalization (Hall et al., 1994).

Silencing by controlling of the topics of conversation is an example of the use of "pastoral power" (Holmes & Gastaldo, 2002; Rabinow, 1984). Pastoral power subtly enforces a normalized way of living. The resulting social control reinforces cultural values and reflects the perspectives of those in control within the culture. The decision by influential staff members to omit information concerning dying and death from the resident and family handbooks at one of the LTC facilities is an example of the exercise of pastoral power. Censoring the discussion of dying and death reflects the preference not to face dying and death that is held by those who have not yet allowed for the possibility, let alone the actuality, of death (Gullickson, 1993). Individuals may also self-censor in order to avoid utterances that would be unacceptable within the social context (Nadelman, 1974). Consequently, thoughts or concerns related to dying or death may remain unvoiced within a setting that prefers to be known as a place for living, not for dying.

A post structural analysis of the influence of power relationships on the discourse on dying and death within LTC facilities could predict the development of resistance to a death-avoiding discourse, and the rise of a counter discourse from the marginalized oldest-old (Hall, 1999; Holmes & Gastaldo, 2002; Rabinow, 1984). However, the formation of a counter discourse may be difficult given the impact on social networks of physical and/or cognitive decline, residential relocation, and the death of peers (Agich, 2003). To the extent that this is so, the reflective processing of the psychic effects of marginalization (Hall et al., 1994) may be a relatively solitary endeavour for the oldest-old in LTC facilities.

Johnson and Barer (1997) observed increased interiority in their investigation of the life-world of a community-dwelling population aged 85 years and older in a California neighbourhood. Whether their tendency to have more a solitary lifestyle is best understood as a chosen mode of adaptation as Johnson and Barer (1997) suggested, or the unavoidable consequence of marginalization, is questionable. Regardless, *interiority* has been described as the existential experience of “a journey to an unknown land where we cannot take our human props, but must take our human weakness” (Oppenheimer, 1999, p. 42). Interiority refers to a contemplative state of mind in which individuals are able to transcend the challenges they face with equanimity. As such, interiority is integral to the processing of spiritual and existential needs. Unfortunately, previous work suggests that the spiritual or existential needs of residents of LTC facilities have been among their more poorly met needs (Albinsson & Strang, 2002; Jones & Wright, 2008; Scocco et al., 2006; Ternestedt & Franklin, 2006; Timonen & O’Dwyre, 2009).

To the extent that the oldest-old represent the inevitability of aging and mortality, approaching the EOL in advanced old-age can be challenging for all concerned. Froggatt (2001a) characterized nursing homes as a means for sequestering elderly individuals whose demise toward death is challenging in a death-avoiding culture. As residents of LTC facilities are removed from active social engagement, they are less empowered to exert agency for themselves or with others (Froggatt, 2001a). Consequently, the institutionalized oldest-old can become the *different other* as described by Myhrvold (2006, p. 127).

The different other is anyone who has suffered extensive losses of his or her life context (Myhrvold, 2006). The experience of the different other threatens the sense of vulnerability of those who encounter them (Myhrvold, 2006; Schultz

& Carnevale, 1996). To manage the resulting fear, the other must be seen to be vulnerable to factors that do not pose the same risk to the observer. Hence, as the other, the oldest-old must be seen as either enough like the observer to pose no threat to his/her own sense of integrity, or different enough to be legitimately “othered” (Myhrvold, 2006). To be like the observer, the oldest-old must be perceived as *living.* To be acceptably different, they must be *dead.* In this research study, this differentiation appeared to be accomplished by delaying the recognition of dying until death was imminent to within a few days or hours. Hence, there was a very brief, if any, living-dying interval (Phillips, 1992) during which it was possible to die, even if not actually dying; and little opportunity to acknowledge and respond to the residents’ mortality authentically (Gullickson, 1993). The concept of transition, as a process of acknowledgement and integration of changed circumstances and possibilities in life (Meleis et al., 2000), has limited applicability under these circumstances as the initial change that a process of transition is not acknowledged.

At the same time, while the oldest-old in LTC facilities are at risk of being held at a distance or marginalized, social conscience demands that the injustices of ageism be avoided. Care planning and clinical decision making can thus become complicated matters of avoiding futile interventions without denying opportunities for the fullness of life. These decisions may be informed by dichotomous thinking that presents a choice between whether one is considered to be living or dying, the strong and pervasive allegiance to life, and the valuing of life equally for everyone, without regard for age (Badger, 2005; Forbes et al., 2000; Jacobs, Bonuck, Burton, & Mulvihill, 2002; Kaufman, 1998; Kaufman et al., 2004; Travis et al., 2001).

Death in advanced old-age has been characterized as *hidden and unacknowledged*, even within the field of palliative care (O'Connor & Bullwinkel, 2009). O'Connor and Bullwinkle proposed that a discourse on d*ecrepit dying* is therefore necessary to recognize ordinary and expected death in advanced old-age. Although the term *decrepit dying* may be repulsive, particularly within an age- and death- avoiding culture, acknowledgement of decrepit dying may be a necessary precursor to advancing knowledge, policy, and program developments that are relevant to the oldest-old who live and die in LTC facilities.

During the 12 month period during which the data for this research study were collected, about 1/3 of the residents of the three participating LTC facilities died. The administrators of these facilities reported that this was an expected rate of "turn over," and also that it was consistent with patterns in LTC facilities across the province. One fifth of the 182 decedents whose charts were reviewed in this research study had died during the first 12 months after their admission to the LTC facility. As shown in Table 1, death was typically attributed to causes that are characterized by a slow decline into the end-stages of progressive chronic diseases and frailty. Yet, this study showed that it was rare, and also considered as inappropriate, for staff members to think that residents were dying until the last hours or few days before death. Thus, it seems that residents of LTC facilities residents could be considered to be marginalized by the attribution of the status of *living* and denial of the approach of the end-of-life.

Within the palliative care philosophy, the ironically privileged status as one who is *dying* opens the possibility to live to the fullest, while at the same time, acknowledging and participating in dying well in a context of open awareness (Byock, 2003; Glaser & Strauss, 1965). In this research study, although residents, family members, and staff members acknowledged an acceptance of impending death in their interviews, dying status was not granted to residents of the participating LTC facilities until within a few hours or days of death, often not until they were very limited in cognitive and physical abilities. Thus, much of the approach to death occurred in a context of mutual pretense (Glaser & Strauss, 1965) in which the reality of impending death was known by all, yet acknowledged by none until death was only hours, or a day or two away. Hence, dying residents, and their families, may have missed opportunities for resolution of relationships or business arrangements, timely palliative pain and symptom management, or EOL care planning that can be possible when the reality of impending death is acknowledged in a more timely fashion. Under existing circumstances, the quality of dying in LTC facilities is dependant on the quality of living there. Hence, the approach to the end of life in LTC facilities is mediated by their everyday culture. Selected elements of the contemporary discourse on the culture of LTC facilities as mediators to both living and the approach to the end of life are discussed in the following section.

Discussion related to Question Two: How does LTC culture influence awareness of impending death and living with that awareness for participants (residents, family members, and staff)?

The belief that LTC facilities are for living appeared to play a significant role in the late acknowledgement of impending death in the three LTC facilities that were study sites in this research study. This belief is consistent with the contemporary discourse concerning LTC facilities which has arisen to challenge an older and more dismal discourse which is discussed below.

The Discourse of Long-Term Care. The contemporary discourse concerning LTC facilities counters their heritage as poor houses at the turn of the century (Achenbaum, 1974). Achenbaum described the period of 1865-1914 as a time when "nearly every favorable belief about the usefulness and merits of age" (p. 39) was challenged, and old-age was a problem without a cure. Frail elders without family and/or wealth to purchase care providers became "inmates" of almshouses where they would die with only the most minimal custodial care. Despite then becoming part of a continuum of health care services in many western societies, nursing homes continued to be characterized as the backwaters of the health care system into the 1960s and 1970s as illustrated by the following quotations:

> To both the general public and to social scientists, life in a nursing home has come to mean decay, cruelty, and dehumanization. (Gubrium, 1975, preface); and
>
> Patient neglect and generally poor treatment are already

> widespread and the public need only continue to do nothing for conditions to worsen (Townsend, 1971, pp. xiv-xv).

Both Gubrium and Townsend acknowledged a need for significant improvements in staff competence, programming, standards of care, and regulation. Since the 1970s, there has been considerable LTC reform, including the development and enforcement of more rigorous care standards, attention to building safety, and the adoption of social models of care (Capitman, Leutz, Bishop, & Casler, 2005). Nevertheless, nursing homes continue to be portrayed recently as undesirable options for the aged and infirm in monographs such as Rosofsky's (2009) *Nasty, Brutish and Long: Adventures in Old Age and the World of Eldercare.*

Empirical studies echo Rosofsky's (2009) journalistic critique of life in contemporary nursing homes. Kayser-Jones (2009) noted inadequate nutritional care and little opportunity for residents to exercise in her observational study of two American nursing homes. Kayser-Jones concluded that nursing homes actually promote dependency among their residents. While staff members were conscientious and concerned about the adequacy of the care they were able to provide, under-staffing, particularly with licensed staff, limited what was possible to accomplish. Temkin-Greener et al. (2009) reported that facilities with greater emphasis on staff education and better registered/certified staffing ratios scored higher on measures of several EOL-care processes including assessment, delivery and coordination of care, and communication.

Based on a content analysis of interviews with nursing home staff, Dwyer et al. (2009) noted that Swedish nursing home staff members experienced the disparity between the quality of care that they would like to provide and what was possible to provide as moral conflict. They recognized that residents' dignity and person-centred care were compromised as consequences of inadequate resources of time and inadequately trained staff. Similarly, in Timonen and O'Dwyer's (2009) study, residents reported that while their most basic physical needs were met, needs related to self esteem, independence, privacy, and self actualization were compromised by staff-centred work routines that enabled the provision of essential care with minimal resources. Interviews with unionized workers in Canadian LTC facilities revealed similar concerns (Armstrong et al., 2009). As contextual factors in nursing homes, understaffing and low levels of education of staff are elements of the culture of LTC facilities. Armstrong et al. (2009) concluded that the single most important barrier to treating residents of LTC facilities with dignity and respect was inadequate staffing. Residents, family members and staff member who participated in this research study reported similar concerns about the impact of low staff to resident ratios on timely and dignified care. In this research study, it was the improved attentiveness and immediacy of response to dying residents' needs for a short period before death, often referred to as "pulling out all the stops", that was recognized as facilitating a good death.

Sadly, the time prior to clinical death, when residents are considered to be living in LTC facilities, has been characterized as a period of social death as residents are sequestered in stubbornly institutional settings (Froggatt, 2001a; Small et al., 2007). Staff members in this and other investigations (Armstrong et al. 2009; Hov et al., 2009) were aware of poor public opinion about LTC facilities. Staff participants in this research study adamantly opposed the popular discourse that nursing homes are “heaven’s waiting rooms” and “dismal last resorts”. They claimed that the public continues to hold opinions that are dated and out-of-touch with current realities in contemporary LTC facilities. They emphasized the changed physical environment (two facilities were less than 10 years old and the third had been radically renovated to appear more home-like), enhanced recreational programming, increased opportunities for resident and family input, and the commitment of a core of long-time care staff members. Like nurses in Hov et al.’s study, staff participants from all departments within the facilities in this research took pride in their work. They were especially proud to be trust-worthy in close relationships with residents for whom they were “like family,” and to “go the extra mile” to make sure that residents did not die alone or in pain. Participation in this research study had offered an opportunity for staff members to voice a counter discourse (Foucault, cited in Rabinow, 1984) from within LTC facilities. Their counter discourse challenged the prevailing negative characterization of nursing homes. According to Timmermans (2010), the counter discourse can be summarized as follows: “Long-term care used to be a big dark unfriendly formidable ’place’ that those being admitted to referred to as the ’end’. I am happy to shout to one and all that ’the nursing home’ is a happening place”.

One of the inadvertent consequences of the counter discourse in LTC may be to dismiss, more completely than is helpful, the belief that frail or dependant people go to LTC facilities to die. Emphasizing *living* in LTC, and separating living from dying, even for very frail and dependant individuals in advanced old-age, offers a perspective that may be palatable for a death-avoiding public. However, a single-minded emphasis on living may disenfranchise the frailest of LTC facility residents from the opportunities or resources that others who are acknowledged to be dying can access. As the Quarterly Reviews of residents provide the data on which the provincial Ministry of Health and Long-Term Care makes policy and funding decisions, it is significant that in this research study, an increased need for support was identified for only half of residents, and that only 1 of 182 residents had been identified as being terminally ill at the last Quarterly Review prior to death. The real nature of palliative/EOL needs in the approach to the end of life in these LTC facilities can thus remain invisible within the health care system, and within policy decisions.

In contrast, managers at the hospital palliative care unit and in community palliative care programs in the locale where this research study was completed, report that there is detailed reporting about the nature and extent of EOL care that is provided in those settings (T. Morris, personal communication, June 13, 2011; L. Weiss, personal communication June 13, 2011). These hospital and community-based programs are known for their more appropriate staffing ratios with registered nursing staff, excellence in pain and symptom management, attention to psychosocial and spiritual needs, multi-disciplinary teamwork, innovative approaches to meeting individuals' wishes, family-focused philosophy, and the uniquely caring nature of the staff who choose to work there (T. Morris, personal communication, June 13, 2011; L. Weiss, personal communication June

13, 2011). These essentials of palliative care for people who are known to be dying may not be available to nursing home residents when the prevailing culture discourages the acknowledgment of dying until the last few days, or even hours, before death as was the case in the settings where this research study was conducted.

Limitations of this Research Study

This research study presents an analysis of awareness of impending death in three LTC facilities in a small city in central Ontario, Canada. Although their circumstances may be similar to many other nursing homes across the province and across Canada, the intent of the research was not to be representative or generalizable. Similarly, while literature from Australia, the United Kingdom, and the United States of America suggests notable similarities in LTC facilities in those countries compared to the settings in this research, the findings reported here should not be generalized without careful consideration of the potential differences in international contexts. In particular, it should be noted that the settings for this research were relatively homogeneous with respect to ethnicity.

Efforts were made to neutralize or account for the researcher’s subjectivity in the research process. However, it is acknowledged that this analysis may have been influenced by the lens through which the culture of LTC was observed and interpreted.

A number of limitations may have influenced this research study, not the least of which is that the researcher is a novice qualitative researcher. Close supervision by a scholar who is experienced in both the substantive field and research methods has helped to mitigate this limitation. A sample of interview transcripts was reviewed by three colleagues. They concurred with initial coding, the development of themes, and finally, with the statements of beliefs related to awareness of dying in the culture of LTC as illustrated by the quotations.

It is also acknowledged that individuals who volunteer to participate in research interviews may well not be representative of others who do not volunteer. In particular, residents who were not physically or cognitively well enough to participate, and family members who did not live in the locale or were reluctant to consider dying and death were not included in this research study. Nevertheless, the findings of this research study and their interpretation are offered as legitimate and significant in understanding the influence of the culture of LTC on the development of awareness of impending death among the oldest-old in LTC facilities.

Chapter Summary

This chapter has provided a discussion of the findings of this research study concerning the influence of the culture of LTC facilities on awareness of impending death. In the context of a death-avoiding society and in the absence of a palliative discourse that accounts for the uncertain and lingering end-of-life trajectory experienced by most residents of LTC facilities, dying was acknowledged just in time to initiate pain relief measures and to ensure that someone would be present with the resident at the time of death. As a result, participants in the culture of these LTC facilities could maintain their belief that residents were living rather than dying for all but a few hours or days prior to their deaths. The inadequacy of palliative care for residents of LTC facilities that have been identified by other researchers and cited in Chapter Two may be due, at least in part, to opposition to the persistent attitude that LTC facilities are dismal places where frail elderly people are left to die. An inadvertent consequence of single-minded loyalty the discourse of *living* LTC facilities may be to marginalize their frail elderly residents with respect to a palliative approach to care.

Chapter 6 – Summary and Implications of This Research Study

As outlined in Chapter Two, the oldest-old, particularly those whose limitations have necessitated admission to LTC facilities, constitute a distinct and often overlooked population. They constitute a population for whom dying and death are arguably predictable and imminent. Yet the oldest-old have received scant attention within the evolution of palliative care research, policy development, and practice. Recent inquiry into dying and death in LTC facilities has revealed inadequacies in the quality of pain and symptom management, psychosocial and spiritual care, culturally appropriate care, and attention to the needs of family members. The most commonly cited reasons for these inadequacies are a lack of well trained staff and the absence of clear prognostic makers along the trajectories of increasing frailty and exacerbating chronic illness. Previous research has not considered the influence of assumptions, beliefs values, and contextual factors that constitute the prevailing culture about dying and death within LTC facilities on EOL care.

This research study addressed this gap using a two-step mixed methods approach in three LTC facilities in a small city in south central Ontario. The first step established the context for the second step. In the first step the population that died over a 12 month period was described based on a review of decedent records. In the second stage, ethnographic methods were used to uncover assumptions, beliefs, values, and contextual factors that influenced the development of awareness of impending death among residents, staff, and family members of residents in LTC facilities.

As outlined in Chapter Four, the mean duration of residence in the three LTC facilities from admission to death was approximately 3 years, over which time residents typically became increasingly frail. Dementia and other chronic progressive diseases, such as chronic congestive heart failure and pneumonia, were the most common causes of death. Deaths in these three nursing homes commonly occurred within a day or two of the resident having been declared palliative.

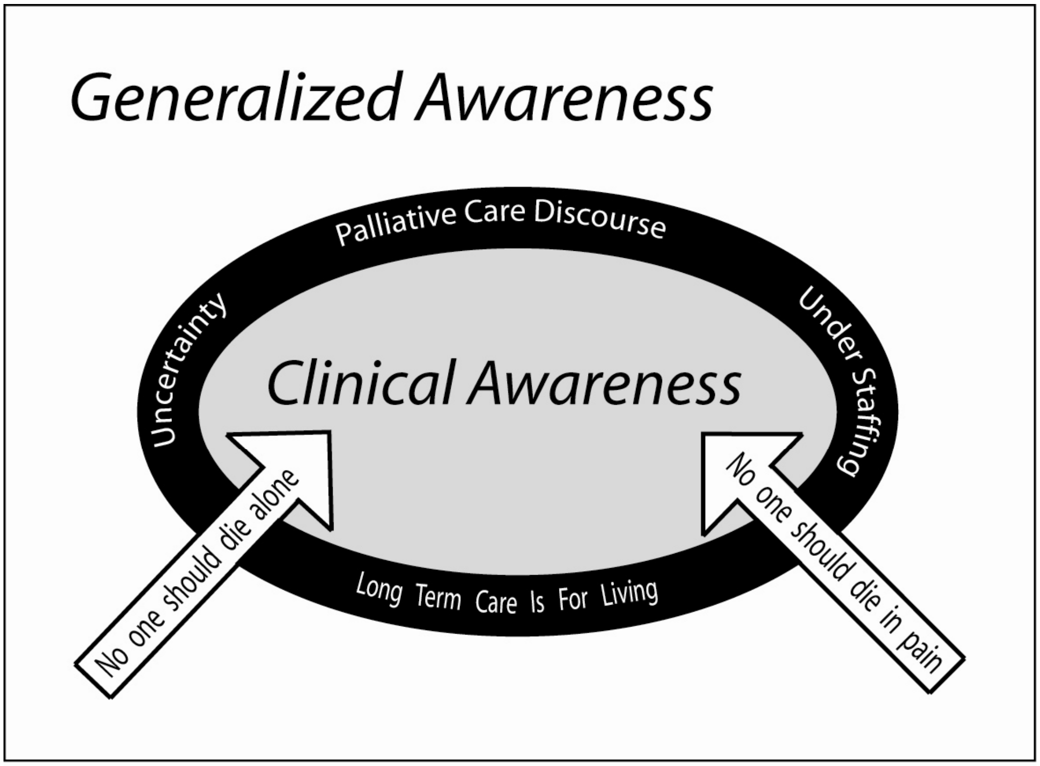
The awareness of impending death in LTC facilities was layered. A generalized awareness of impending death was maintained as an abstract, background reality while the activities and conditions of ordinary living in these LTC facilities continued, often until within a few days or hours of death. Clinical awareness of impending death was acknowledged only when significant changes in the resident’s clinical status necessitated a change in the distribution of resources to facilitate palliative measures through the last few hours or days before death. The belief that LTC facilities are places for living, not places to go to die, and the context of limited resources were identified as barriers to the adoption of a palliative approach to care in advance of the obvious acute stage of dying. The beliefs that residents should not die alone or suffer in dying were bridges from philosophical to clinical awareness of impending death, and the resultant institution of palliative measures. The relationship of cultural influences in the study sites and awareness of impending death is illustrated in Figure 1. An earlier adoption of a palliative approach to care will require improvements not only in LTC resources, notably an increase in well trained staff, but a revision of the culture of LTC to embrace dying as a reality for the oldest-old who live ever-nearer to the end of life in LTC facilities.

The findings of this research study suggest that, consistent with strongly held beliefs about EOL care, impending death in the participating LTC facilities is acknowledged just in time to facilitate late or end-stage pain and symptom management and to plan for someone to be present with the resident as death occurs. It appears that an earlier and more comprehensive palliative approach to care, such as that recommended by the Canadian Hospice Palliative Care Association (n. d.), is unlikely within the existing culture of these LTC facilities. The existing culture emphasizes living and turns away from dying, even though many within the resident population are predictably near the end of life by virtue of advanced old-age and frailty. A palliative approach to care would acknowledge the reality of impending death and plan for its approach, even when the exact time is difficult to predict. A palliative approach to care would give priority to dignity and comfort for longer than the final few hours or days of life for residents of LTC facilities (Canadian Hospice Palliative Care Association, n. d.). Considering the data regarding length of stay in LTC facilities and the common trajectories of decline between admission and death, a palliative approach to care could be instituted from the time of admission. However, allegiance to the discourse of living in LTC facilities argues against considering residents of nursing homes to be dying. Advanced old-age and frailty have yet to be recognized as indicators of impending death.

In the absence of a palliative discourse that recognizes the uniqueness of the trajectory of chronic decline and increasing frailty, it is all but impossible to discuss impending death of the oldest-old, or anyone else, in LTC facilities. Those who do attempt to engage in this discussion risk being seen as exercising ageist judgments about the value of the individuals who are in advanced old-age, or misunderstanding the new and improved LTC system. Meanwhile, residents may not benefit from a palliative approach to care, for most of the duration of their stay in LTC facilities despite their inevitable approach to death. Palliative measures that reflect the beliefs that residents should not die alone or in pain are commonly initiated in the last few days of life, thus reducing palliative care to late-stage or end-stage pain and symptom management. Prior to that, residents continue to live the best life that is possible in an environment that is considerably impacted by chronic under funding and averse to being seen as a place for dying.

Improving the journey toward death while living in LTC facilities would require acknowledging that residents are dying as they are living. The aged may not fear dying in LTC facilities. They do fear the prospect of living in there (Bradley et al., 2010; Grundy & Bowling, 1999; Hall, Longhurst & Higginson, 2009; Jeon et al., 2006; Pleschberger, 2007; Scocco et al., 2006; Stafford, 2003). The adoption of a palliative approach in LTC facilities would facilitate the best quality of living while approaching the end of life. A palliative approach would neither give up on, nor devalue the person (Canadian Hospice Palliative Care Association, n. d.). Rather, it would acknowledge the significance of advanced old-age and the reality of a finite human life span as elements of person-centred care from the time of admission, and not just when clinical signs predict death within a few days. The adoption of a palliative approach to care would require significant change in the current culture of LTC facilities, including the development of policies, standards of care, best practices recommendations, and increased funding to provide adequate levels of appropriately trained care staff. However, without a dramatic shift in the discourse of dying in LTC facilities, enhanced policies and increased funding are unlikely to change the approach to the end of life. Rather, all who participate or contribute to the culture of LTC facilities will need to embrace the nursing home as a centre of excellence for care of the dying.

*Figure 1.*Relationship of Cultural Influences on Awareness of Impending Death*



* Generalized awareness was evident in the words of residents, family members and staff members. Clinical awareness was clearly evident in the words of staff members and among some family members. Other family members did not have the knowledge or confidence to recognize the clinical signs of impending death. These family members relied on staff members to interpret their observations.

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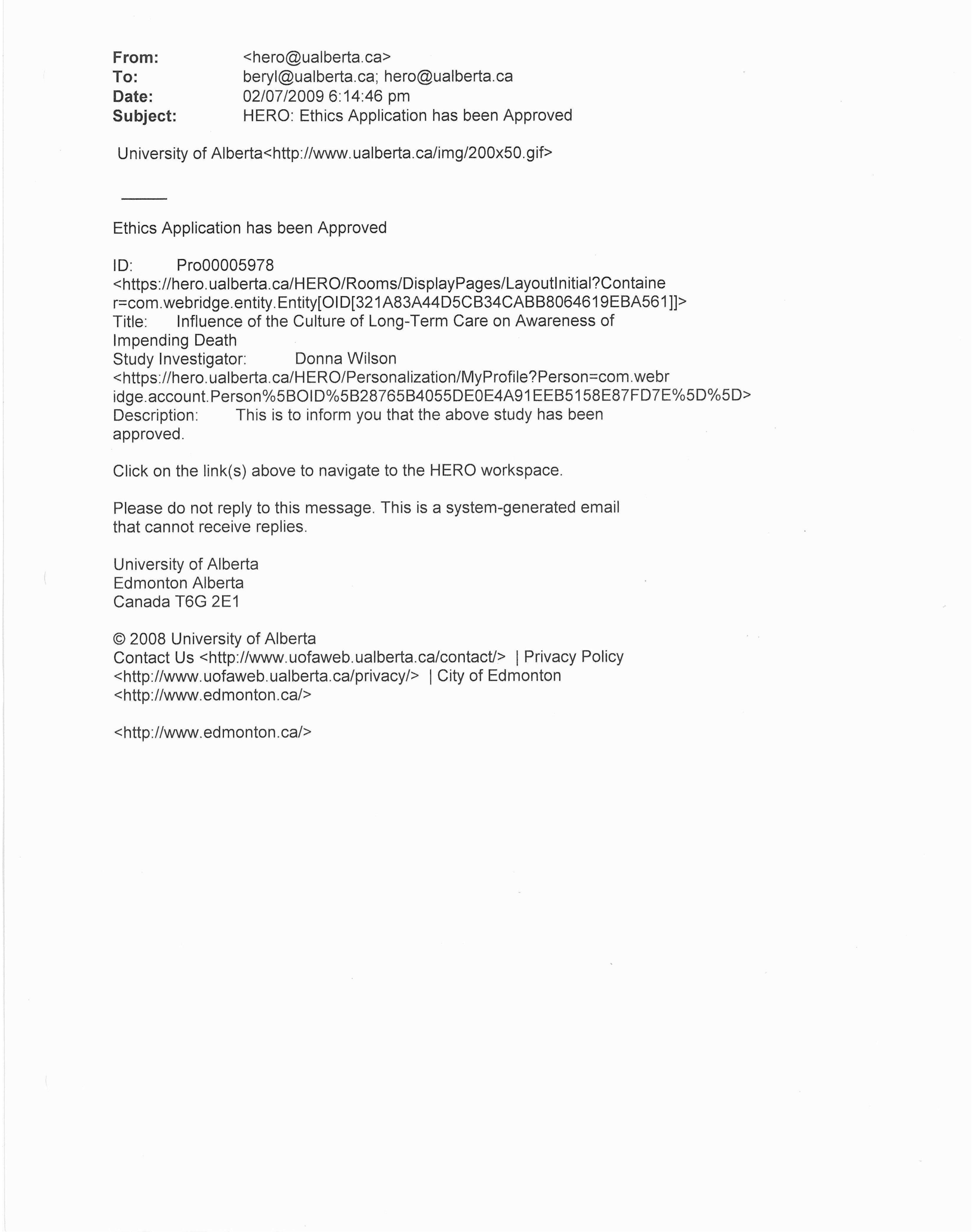
Appendix A

University of Alberta Human Research Ethics Board Notice of Approval



From: <hero@ualberta.ca>
To: beryl@ualberta.ca; hero@ualberta.ca
Date: 02/07/2009 6:14:46 pm
Subject: HERO: Ethics Application has been Approved

University of Alberta<http://www.ualberta.ca/img/200x50.gif>

Ethics Application has been Approved

ID: Pro00005978
<https://hero.ualberta.ca/HERO/Rooms/DisplayPages/LayoutInitial?Container=com.webridge.entity.Entity[OID[321A83A44D5CB34CABB8064619EBA561]]>
Title: Influence of the Culture of Long-Term Care on Awareness of Impending Death
Study Investigator: Donna Wilson
<https://hero.ualberta.ca/HERO/Personalization/MyProfile?Person=com.webridge.account.Person%5BOID%5B28765B4055DE0E4A91EEB5158E87FD7E%5D%5D>
Description: This is to inform you that the above study has been approved.

Click on the link(s) above to navigate to the HERO workspace.

Please do not reply to this message. This is a system-generated email that cannot receive replies.

University of Alberta
Edmonton Alberta
Canada T6G 2E1

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Appendix B

Information for Potential Family Research Participants – Post Death

The University of Alberta

Information sheet for potential research participants

Title of study:

An Exploration of the Influence of the Culture of Long-Term Care on Awareness of Impending Death

Investigator: Beryl Cable-Williams, PhD student

Background: Family members of people who die in long-term care facilities have often been asked to make decisions related to the care of their loved one at the end of his or life. However, family members have rarely been asked about their thoughts and feelings about their loved one's approaching death, or how they came to realize that death was immanent. It would be helpful for those who make plan and provide care to know how family members think about the impending death.

Purpose: This study will help caregivers understand the thoughts of family members about nearing the end of a loved one's life, from their perspective following the death of a loved one.

Procedures: If you agree to participate, you will be interviewed as an individual. You will be asked to consider your thoughts about your family member's life and the time leading to her/his death. An interview is not likely to take longer than 1 ½ hours. You may end the interview at any time. It may be much shorter. Interviews will take place at a time and in a setting of your choice. You will have a choice to have the interview audio-taped or not. You may be contacted again with an opportunity to take part in a small group discussion of a few questions when all the interviews are completed. You can choose to participate in an interview, or small group discussion, or both.

Possible Benefits: Any benefit from participation in this study is indirect. There is no payment. Some people will find it interesting or even helpful to discuss their thoughts about living toward the end-of-life in advanced old age. Some people may appreciate the opportunity to consider issues that they had not thought about. Participation in research that can help others may be gratifying.

Possible Risks: Any risk from participation in this study is considered to be indirect and minimal. There are no medications or invasive procedures involved. Some people may have an emotional response to some of the topics that arise in conversation. The researcher will make information available about sources of support including the local grief and bereavement support services. The researcher will initiate a referral at the request of the research participant.

Confidentiality: Any notes taken during the interview and any tape recordings will be kept confidential. In compliance with University of Alberta requirements, after the data has been analyzed it will be stored for a period of 5 years in a locked storage file in the office of Dr. D. M. Wilson at the University of Alberta. No identifying information will be retained. No identifying information will be presented in any written or verbal report of the research.

Voluntary Participation: You can ask any questions prior to signing the consent form or providing verbal consent. You can ask questions at any other time during your participation. You are free to end your participation at any time. No explanation will be required. There will be no negative consequences for you or your family member's care for withdrawing.

Contact Names and Telephone Numbers:

If you have any concerns about any aspect of your participation in this study, you may contact the

University of Alberta Human Research Ethics Board by calling collect 1-780-492-0302. This office has no affiliation with the study investigators.

Please contact Beryl Cable-Williams at 905-342-2858 or emailberyl@ualberta.ca if you have any questions about becoming involved as a research participant, or contact Dr. D. M. Wilson at 1-780-492-5574 if you have questions about the research.

Appendix C

Information for Potential Family Research Participants

The University of Alberta

Information sheet for potential research participants

Title of study:

An Exploration of the Influence of the Culture of Long-Term Care on Awareness of Impending Death

Investigator: Beryl Cable-Williams, PhD student

Background: Family members are often asked to make decisions related to the care of their loved one at the end of his or life. However, family members are rarely asked about their thoughts and feelings about their loved one's approaching death. It would be helpful for those who make plan and provide care to know how family members think about the impending death.

Purpose: This study will help caregivers understand the thoughts of family members about nearing the end of a loved one's life.

Procedures: If you agree to participate, you will be interviewed as an individual. You will be asked to consider your thoughts about your family member's life, past present and future, including the inevitability of her/his death. An interview is not likely to take longer than 1 ½ hours. You may end the interview at any time. It may be much shorter. Interviews will take place at a time and in a setting of your choice. You will have a choice to have the interview audio-taped or not. You may be contacted again with an opportunity to take part in a small group discussion of a few questions when all the interviews are completed. You can choose to participate in an interview, or small group discussion, or both.

Possible Benefits: Any benefit from participation in this study is indirect. There is no payment. Some people will find it interesting or even helpful to discuss their thoughts about living toward the end-of-life in advanced old age. Some people may appreciate the opportunity to consider issues that they had not thought about. Participation in research that can help others may be gratifying.

Possible Risks: Any risk from participation in this study is considered to be indirect and minimal. There are no medications or invasive procedures involved. Some people may have an emotional response to some of the topics that arise in conversation. The researcher will make information available about sources of support including the facility's social worker and local grief and bereavement support services. The researcher will initiate a referral at the request of the research participant.

Confidentiality: Any notes taken during the interview and any tape recordings will be kept confidential. In compliance with University of Alberta requirements, after the data has been analyzed it will be stored for a period of 5 years in a locked storage file in the office of Dr. D. M. Wilson at the University of Alberta. No identifying information will be retained. No identifying information will be presented in any written or verbal report of the research.

Voluntary Participation: You can ask any questions prior to signing the consent form or providing verbal consent. You can ask questions at any other time during your participation. You are free to end your participation at any time. No explanation will be required. There will be no negative consequences for you or your family member's care for withdrawing.

Contact Names and Telephone Numbers:

If you have any concerns about any aspect of your participation in this study, you may contact the

University of Alberta Human Research Ethics Board by calling collect 1-780-492-0302. This office has no affiliation with the study investigators.

Please contact Beryl Cable-Williams at 705-748-1011 ext 7900 if you have any questions about becoming involved as a research participant, or contact Dr. D. M. Wilson at 1-780-492-5574 if you have questions about the research.

Appendix D

Information for Potential Resident Research Participants

The University of Alberta

Information sheet for potential research participants

Title of study:

An Exploration of the Influence of the Culture of Long-Term Care on Awareness of Impending Death

Investigator: Beryl Cable-Williams, PhD student

Background: Many people who have a long life will live in a nursing home at some time. Residents are rarely asked their thoughts about their own eventual death. It would be help those who make plans for health services and provide care to know what residents think about nearing the end-of-life in a nursing home.

Purpose: This study will help caregivers know more about what nursing home residents' think about approaching the end of life.

Procedures: If you agree to take part, you will have an individual interview. You will be asked to think about your own past, present and future, including your own eventual death. An interview is not likely to take longer than 1 ½ hours. It may be much shorter. You may end an interview at any time. Interviews will take place at a time and in a setting of your choice. You will have a choice to have the interview audio-taped or not. You may be contacted again with an opportunity to take part in a small group discussion of a few questions when all the interviews are completed. You can choose to participate in an interview, or a small group discussion, or both.

Possible Benefits: Any benefit from taking part in this study is indirect. There is no payment. Some people will find it interesting or even helpful to talk about their thoughts about living toward the end of life in advanced old age. Some people may like to consider issues that they had not thought about. Taking part in research that can help others may be gratifying.

Possible Risks: Any risk from taking part in this study is considered to be indirect and small. There are no medicines or invasive treatments involved. Some people may have an emotional response to some of the topics that arise in the interview. The researcher will make information available about sources of support such as the facility's social worker and local grief support services. The researcher will initiate a referral at the request of the research participant.

Confidentiality: Any notes taken during the interview and any tape recordings will be kept confidential. After the study is complete the data will be stored for a period of 5 years in a locked storage file in the office of Dr. D. M. Wilson. No identifying information will be kept. No identifying information will appear in any written or verbal report.

Voluntary Participation: You can ask any questions prior to signing the consent form or providing verbal consent. You can ask questions at any other time during the interview. You are free to stop at any time. You will not have to give any reasons. There will be no negative impact for you or your care if you withdraw from the study.

Contact Names and Telephone Numbers:

If you have any concerns about any thing that happened when you took part in the study, you may contact the University of Alberta Human Research Ethics Board by calling collect 1-780-492-0302. This office has no affiliation with the researchers.

Please contact Beryl Cable-Williams at 705-748-1011 ext 7900 if you have any questions about taking part in the study. Contact Dr. D. M. Wilson at 1-780-492-5574 if you have questions about the research.

Appendix E

Information for Potential Staff Research Participants

The University of Alberta

Information sheet for potential research participants

Title of study:

An Exploration of the Influence of the Culture of Long-Term Care on Awareness of Impending Death

Investigator: Beryl Cable-Williams, PhD student

Background: Staff members of long-term care facilities have intimate professional relationships with residents. They may be the first to recognize that a resident is nearing the end of his or her life. Yet little is known about how impending death is recognized. Being aware of impending death is the first step in a palliative approach in care. It would be helpful to know how long-term care staff members become aware that death is near.

Purpose: This study will add to what is known about awareness of impending death. It will contribute to improved care at the end of life for residents of nursing homes.

Procedures: If you agree to participate, you will be interviewed as an individual. You will be asked to consider your thoughts about residents including the inevitability of their death. An interview is not likely to take longer than 1 ½ hours. It may be much shorter. Interviews can end at any time as the participant wishes. Interviews will take place at a time and in a setting of your choice. You will have a choice to have the interview audio-taped or not. You may be contacted again with an opportunity to take part in a small group discussion of a few questions when all the interviews are completed. You can choose to participate in an interview, or a small group discussion, or both.

Possible Benefits: Any benefit from participation in this study is indirect. There is no payment. Some people will find it interesting or even helpful to discuss their thoughts about working with people who are living toward the end-of-life in advanced old age. Some people may appreciate the opportunity to consider issues that they had not thought about. Participation in research that can help others may be gratifying.

Possible Risks: Any risk from participation in this study is considered to be indirect and minimal. There are no medications or invasive procedures involved. Some people may have an emotional response to some of the topics that arise in conversation. The researcher will make information available about sources of support including the facility's social worker and local grief and bereavement support services. The researcher will initiate a referral at the request of the research participant.

Confidentiality: Any notes taken during the interview and any tape recordings will be kept confidential. In compliance with University of Alberta requirements, after the data has been analyzed it will be stored for a period of 5 years in a locked storage file in the office of Dr. D. M. Wilson at the University of Alberta. No identifying information will be retained. No identifying information will be presented in any written or verbal report of the research.

Voluntary Participation: You can ask any questions prior to signing the consent form or providing verbal consent. You can ask questions at any other time during your participation. You are free to end your participation at any time. No explanation will be required. There will be no negative consequences for you or your employment if you withdraw from the study.

Contact Names and Telephone Numbers:

If you have any concerns about any aspect of your participation in this study, you may contact the University of Alberta Human Research Ethics Board by calling collect 1-780-492-0302. This office has no affiliation with the study investigators.

Please contact Beryl Cable-Williams at 705-748-1011 ext 7900 if you have any questions about becoming involved as a research participant, or contact Dr. D. M. Wilson at 1-780-492-5574 if you have questions about the research.

Appendix F

Consent Form

The University of Alberta

Consent for Participation in a Research Study

Title of Project: The Influence of the Culture of Long-term Care on Awareness of Impending Death

Principle Investigator: Dr. D. M. Wilson
Co-investigator: Beryl Cable-Williams

Research participants please circle the appropriate response

1. Do you understand that you have been asked to be in a research study?
Yes No

2. Have you received and read or had adequate explanation of the attached information sheet?
Yes No

3. Do you understand the benefits and risk associated with participation in this study?
Yes No

4. Have you had an opportunity to ask questions and discuss the study?
Yes No

5. Do you understand that you are free to withdraw from the study at any time?

Yes No

6. Has the issue of confidentiality been explained to you?
Yes No

7. Do you understand who will have access to the information you provide?

Yes No

8. Who explained this study to you?____

I agree to take part in this study.
Yes No

Signature of research participant
____

Printed name of participant
____

Date____

Statement of Witness: I believe that the person named above understood all the information relevant to providing informed consent to participate in this study, and agreed to participate voluntarily.

Signature of Witness
____

Signature of Investigator
____

Appendix G

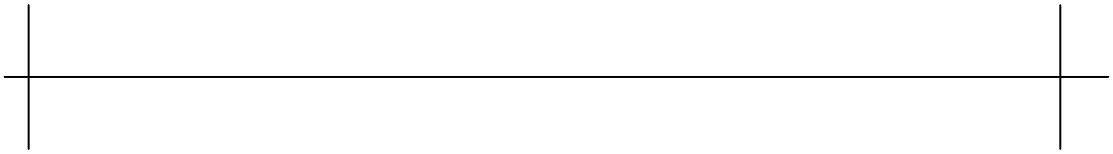
Interview Process – Resident

Thank you for your interest in talking with me about the research I am doing. There is so much we need to know about the thoughts and needs of folks who, like you, have lived very long lives, and now make their home in nursing home.

Do you have any questions for me?

I want to remind you know that you can stop this conversation any time you wish, for any reason. I will not be personally offended, and it will not make any difference in my respect for you, or for your care.

I am interested to know how you see your life, past, present and future. Perhaps we could draw it on a time line so that I can see the important points?



Beginning

End

Where would we be on this time line today?

What have been some significant events or turning points in your life? (Mark these on the time line. Take note of marriages, losses, losses, illnesses, and/or crises. Engage in some dialogue.)

As you look ahead, what do you think the significant points will be?

If the individual initiates conversation about their own dying, note the language, emotional tone, implied beliefs etc. and engage in exploration of these ideas.

If the individual speaks about the death of someone close to them, inquire about awareness of impending death.

If the individual does not make reference to the EOL, comment on the elements that have been identified and note the absence of the EOL in the future on the time line.

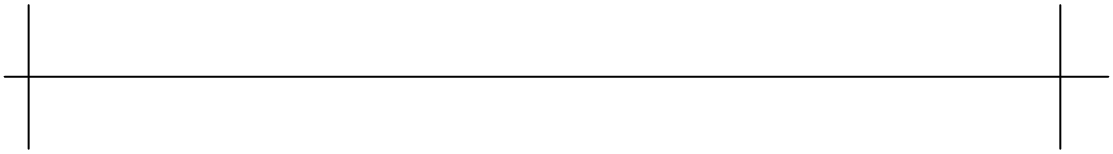
Close the interview with some summarizing and appreciative comments. Inquire about possibility of returning with additional questions to clarify aspects of interest, or for further exploration at another time.

Appendix H

Interview Process - Family Members

Thank you for your interest in the research I am doing. There has been very little research about people who have lived as long as your [mother/father/brother/etc], so there is a lot we need to know in order to be sensitive to their needs, and the needs of family members like you.

I would like to start by getting a sense of how you understand your mother's/father's life, past, present and future. We can use this time line to identify the significant elements:



Beginning

End

Your mother was born in _______?

What were some events in her life that you see as having been very significant?

Where should we put them on this time line?

Comment on the life story.

What strengths do you feel she has at present?

What challenges do you feel she faces now?

What challenges do you feel she faces in the future?

What challenges do you feel that you will face in the future with your mother?

Where do you feel we are on this time line now?

If the interviewee makes reference to proximity to the EOL, note that this topic can be difficult to talk about. Relate to individual sensitivities allowing for either continued conversation or ending of the interview. If the participant wishes to continue:

Do you hope to have some advance notice of the likelihood of death?

What would be important in that time?

What are your expectations from caregivers about the time before his/her death occurs?

How would you like to communicate your wishes/expectations to your mother's caregivers?

Close the interview with some summarizing and appreciative comments. Inquire about possibility of returning with additional questions to clarify aspects of interest, or for further exploration at another time.

Appendix I

Interview - Staff Members

Thank you for your interest in the research that I am doing. I have great respect for the work you do. I am surprised by how little we know about what it is like to work in LTC, particularly when you work with people who have lived a very long time and may not live much longer. I understand that there were ____ deaths in this LTC facility last year. I think you probably have a lot of valuable knowledge that could be helpful to others.

Do you have any questions for me before we begin our discussion?

I want to remind you that everything said in this room goes no further than the door. I will not be reporting any specific comments to any others in the LTC facility.

Is there a palliative care program here?

What is involved in the palliative care program?

Who gets palliative care?

Does anything change for you when a resident is dying?

How is care of a dying resident the same or different from one who is not dying?

How do residents know that they are dying?

How do residents express their awareness of dying?

How do family members know that their loved one is dying?

How do family members express the awareness of impending death?

Are any residents dying at this time here?

How do you know when a resident is going to die soon?

Appendix J

Constant Comparative Analysis adapted from Boeije (2000)

1. Comparison within a single interview	
Sample questions: What is the core message of the interview? Is the interview internally consistent? Are there contradictions within the interview?	Results: Summarize interview Begin concept development Begin conceptual profile Begin memoing
2. Comparison between interviews within same participant group	
Sample questions Are the participants speaking in the same way about the same thing? What are the similarities and differences and what might account for these?	Results Begin preliminary list of concepts/themes Begin clustering of concepts/themes
3. Comparison of interviews from different groups.	
Sample questions What themes appear in the interviews of one than one groups, and which themes appear from some but not all groups? What might account for the similarities and	Results Further development of concepts/themes Additional memos

differences? What do the different groups say about the same themes?	
4. Comparison of themes from interivews, focus groups, and survey data	
Sample questions What themes appear in which data cluster? Which themes appear in some but not all groups? What might account for the similarities and differences?	Results Further development of codes/themes Additional memos

Appendix K

Sample Advanced Directive Form

ADVANC DIRECTIVES: MANAGEMENT OF LIFE THREATENING ILLNESS

This is an agreement between ____________ and ___________. After discussion the resident/family has decided that life-threatening illnesses should be handled in the following manner: (check the appropriate box)

☐ **1. Palliative Level 1**

Keep me comfortable here at _______________
Give me personal care and pain relief
Do not transfer me to hospital
Do not give me medication to prolong my life
Do not attempt to resuscitate me if my heart stops or I cease to breathe
Summary: Let me die comfortably and peacefully

☐ **2. Supportive Care Level 2**

Keep me comfortable here at _______________
Give me personal care and pain relief
Do not transfer me to hospital
Do not attempt to resuscitate me if my heart stops or I cease to breathe
Get me antibiotics and other medications to attempt to cure my illness and prolong my life
Summary Try to cure my illness here at _____ but do not hospitalize me

☐ **3. Moderate Care Level 3**

Send me to the hospital for further care if necessary
Give me intravenous material if recommended by the physician
Operate on me if recommended by the physician
Do not attempt to resuscitate me if my heart stops or I cease to breathe
Do not put me on life-support systems
Summary: Try to cure my illness and hospitalize me if necessary but no heroic measures

☐ **4. Acute care Level 4**

Do everything medically and surgically possible to prolong my life
Resuscitate me in the event of a witnessed event at ________________ or I cease

to breathe
Move me to hospital on life-support systems if necessary, including CPR
Summary: Do everything possible to cure my illness and prolong my life including heroic measures

Additional Directions: This agreement can be changed at any time by the resident/family. The new agreement will be completed and reviewed by family and nursing staff annually.

Date _________________

Signature of resident or decision maker

____

Date _________________

Signature of Witness

____

Reviewed by Physician Signature __________________________ Date ____________