Adult Children Perceptions of the Quality of Hospital Care Received by Their Advanced-Age Parents at the End of Life: A Sequential Mixed Methods Approach

by

Jacqueline M. Crandall

A thesis submitted in partial fulfillment of the requirements for the degree of

Doctor of Philosophy

Faculty of Nursing
University of Alberta

ABSTRACT

Dying advanced-age adults (85+) are at risk of receiving suboptimal end-of-life (EOL) care in hospital, as they are often not recognized as dying. Their children may have important perspectives on quality advanced-age hospital-based EOL care. The aim of this study was to develop a theory of high-quality EOL hospital care for patients aged 85 and older admitted for non-surgical care. The objectives were to: (a) describe older people (aged 85+) who die in hospital, (b) describe the hospital services provided to older persons aged 85+ who die in hospital, and (c) explore adult children's perceptions of the quality of hospital care provided to their parent aged 85+ during the last non-surgical admission that ended in death. The study used a mixed methods quantitative→ QUALITATIVE priority-sequence research design. Decedent demographics and hospital use in the Canadian province of Ontario were determined using data obtained from the Canadian Institute for Health Information's (CIHI) Discharge Abstract Database. Grounded theory methodology guided the qualitative phase of the study where 15 adult children provided information about the EOL hospital care of 12 advanced-age parents.

During the year 2014-2015, 13,450 advanced-age adults died in Ontario acute care hospitals, accounting for 32.7% of all hospital deaths in Ontario. Palliative care was the primary diagnosis in 21.1% of the 13,450 cases. The median length of hospital stay for advanced-age decedents was 6 days, few received life-sustaining treatments in hospital, although 12.0% died in a specialty care unit, such as an intensive care unit. In the qualitative phase, the parent's impending death surprised many adult children. Interviews with adult children resulted in the development of four themes relating to their perceptions of quality EOL care: (a) being an adult child, (b) being an advocate, (c) receiving high (and low) quality EOL care, and (d) reacting and remembering. The third theme of receiving high (and low) quality EOL care consisted of four categories: (a) being informed vs. being left in the dark, (b) receiving compassionate care vs.

being treated uncaringly, (c) being treated with respect and dignity vs. being devalued as a person, and (d) receiving optimal care and comfort vs. falling through the cracks. The findings indicate quality improvement measures are needed to deliver consistent effective, patient-centered EOL care. The devised substantive theory of quality EOL hospital care for advanced-age adults provides a useful framework to guide hospital-based EOL care.

Keywords: end-of-life care; hospital; palliative care; older patients; adult children; care perceptions

PREFACE

This thesis is an original work by Jacqueline Crandall under the supervision of Dr. Donna Wilson. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name "Adult children's perceptions of the hospital care received by their advanced-age parent at the end of life: A sequential mixed methods approach," No. Pro00060204_DATE: January 8th, 2016. The Canadian Institute of Health Information provided access to the Discharge Abstract Database for this project through the Graduate Student Data Access Program (GSDAP): Request number 4107.

ACKNOWLEDGEMENTS

This dissertation would not have been possible without the support and guidance of many individuals and organizations. I am truly grateful for the mentorship and expertise of my supervisor, Dr. Donna M. Wilson. She has expanded my thinking, challenged my writing, and introduced me to end-of-life care researchers around the world. Thank you to my committee members for their extremely valuable and insightful suggestions; you have been a great support. Thank you, also, to Dr. Cohen, who so willingly accepted the external evaluator role and joined the dissertation defense late in the evening from Belgium. I feel truly blessed to have been connected to such a knowledgeable team of researchers.

Thank you to the many organizations who provided support through awards: (a) the Canadian Nurses Foundation; (b) the University of Alberta, including the Aging and Quality of Life Research Unit; (c) the London Health Sciences Centre; (d) the Canadian Gerontological Nursing Association; and (e) the Nurse Practitioners' Association of Ontario. Thank you, also to the Canadian Institute of Health Information. With your assistance, I began an exciting learning journey into the world of linking hospital metrics to patient/family experience. Thank you to my supervisors at the London Health Sciences Centre in Ontario, Janice McCallum and Sherri Lawson, for your flexibility and support with granting me time to complete my studies. I am also grateful to my colleagues for their expressions of encouragement and celebration.

A special thank you to the families that I have worked with. You have opened your homes and hearts as you shared stories about loss, joy, and the importance of quality EOL care for your parent. For this, I am truly grateful. Lastly, thank you to my family for their unconditional love, understanding, and support throughout this PhD journey. To my husband (Bob), my daughters (Denise, Candace, and Krista) and their families, and my parents (Andre and Shirley, Glen and Evelyn) and extended family, I couldn't have done it without you!

TABLE OF CONTENTS

LIST OF TABLES

Table Page

LIST OF FIGURES

CHAPTER ONE

BACKGROUND AND SIGNIFICANCE OF THE STUDY

Ensuring all Canadians have access to high-quality end-of-life (EOL) care is a national priority (Canadian Hospice Palliative Care Association [CHPCA], 2015; Local Health Integration Networks & Quality Hospice Palliative Care Coalition of Ontario, 2011; Ministry of Health and Long-Term Care [MHLTC], 2016b; Quality End-of-Life Care Coalition of Canada, [QELCCC] 2010). While progress has been made toward meeting this priority (CHPCA, 2015; MHLTC, 2016b), there is a growing body of evidence that suggests advanced-age adults (aged 85+) are at risk of receiving sub-optimal end-of-life (EOL) care (Gardiner, Cobb, Gott, & Ingleton, 2011; Lloyd et al., 2016; Unroe & Meier, 2013; Wenger & Rosenfeld, 2001). One stated reason for sub-optimal care is that early signs of dying are often less clear for this age group, and so dying may be unrecognized (Lloyd et al., 2016). Evidence also demonstrates that advanced-age adults have less access to hospice and specialist palliative care services, poorer symptom control in the last days of life, low matching of patient treatment preferences to treatment received, and also potentially inappropriate cure-oriented treatment in hospital (Cook & Rocker, 2013; Hunt, Shlomo, & Addington-Hall, 2014a; Morrison, 2013; Paice, Muir, & Shott, 2004; Thurston, Wilson, & Hewitt, 2011; Unroe & Meier, 2013; Verhofstede et al., 2016; Wilson, & Hewitt, 2017).

Seriously-ill advanced-age adults represent a rapidly growing and complex group of individuals (Hunt et al., 2014a; Northcott & Wilson, 2016; Statistics Canada, 2013). As some advanced-age adults die in hospital, high-quality EOL care in hospital is needed to meet the holistic needs of this population (Davies & Higginson, 2004; Gardiner et al., 2011; Gomes, Cohen, Deliens, & Higginson, 2011; Hall, Petkova, Tsouros, Costantini, & Higginson, 2011; Natan, Garfinkel, & Shachar, 2010). However, there is a dearth of literature focusing on the quality of EOL care received by the advanced-age population (Cable-Williams, 2011; Lloyd-Williams, Kennedy, Sixsmith, & Sixsmith, 2007). Hospitals need a better understanding of the care provided to advanced-age adults at the end of life to enhance the quality of EOL care provided to this population.

This chapter outlines salient definitions used throughout the completed study. Challenges facing advanced-age adults as they approach the end of life are reviewed, and the chapter concludes with the aim and significance of this study.

Salient Definitions

This study utilized the terms "quality EOL care," "advanced-age adults," "hospital care," "adult children," and "non-surgical admission." "Quality EOL care" refers to care that is provided at the end of life that meets the needs and expectations of the patient and family, is reasonably consistent with their wishes, and reduces suffering and improves the quality of life of the dying person and family. The term "advanced-age adults" refers to adults aged 85 and over. "Adult children" are defined as adult sons or daughters, step-sons or step-daughters, sons-in-law and daughters-in-law, grandchildren, and anyone else aged 18 or over who perceives the advanced-age adult to be their parent. The term "hospital care" refers to the care received in an acute care hospital during the last hospital stay ending in death in hospital. The term "non-surgical admission" refers to hospitalized patients who did not receive surgery during the final hospital stay. Examples of non-surgical conditions include pneumonia, congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), and cancer. The qualitative portion of this study excludes surgical patients to avoid deaths that occur because of surgical complications, trauma (excluding falls), and potentially reversible conditions where a return to health is considered possible with surgical intervention.

Background

In the 2016-2017 year, 278,501 people died in Canada (Statistics Canada, 2017a). Of those, 35.6% (99,038) were 85 years of age and over; an increase from the 29.3% (68,524) who died 10 years earlier (Statistics Canada, 2017a). For many years, the greater majority of deaths in Canada have occurred in hospitals (Ahmad & O'Mahony, 2005; Fowler & Hammer, 2013; Statistics Canada, 2013; Wilson et al., 2009). However, an out-of-hospital shift is occurring, with 43.7% of deaths in all parts of Canada except Quebec having taken place in acute care hospitals in the 2014-2015 year (Wilson, Shen, & Birch, 2017).

Advanced-age adults often have unique EOL care needs as compared to younger people because of their age and its effects on cognitive and physical health, and the types of illnesses and disease trajectories that they are likely to suffer from (Gomes et al., 2011; Hall et al., 2011; Lloyd et al., 2016; Olden, Holloway, Ladwig, Quill, & van Wijngaarden, 2011). As compared to younger people, advanced-age adults more often have chronic illness diagnoses such as dementia, congestive heart failure (CHF), and chronic obstructive lung disease (COPD) (Olden et al., 2011). These diseases have more unpredictable death trajectories than the terminal death trajectory that is more common among younger people (Gomes et al., 2011; Hall et al., 2011; Olden et al., 2011). As such, signs indicating that advanced-age adults are dying are less often recognized (Huijberts, Buurman, & de Rooij, 2016). Moreover, hospitalized older persons with organ failure and frailty have higher rates of delirium, cognitive decline, and functional disability, and, as a result, are often less capable of making their own medical decisions as compared to younger people (Huijberts et al., 2016; Olden et al., 2011).

Although most people would like to die at home now, for various reasons, many people still die in hospital (Gomes et al., 2011; Hunt et al., 2014a; Wilson et al., 2009; Wilson et al., 2017). This death site may be because many dying older and advanced-age adults are concerned about being a burden on others (Gott, Seymour, Bellamy, Clark, & Ahmedzai, 2004). In addition, older and advanced-age adults may believe a better quality of care can be delivered in hospital (Gott et al., 2004; Hunt et al., 2014a). Moreover, many are unable to die at home because they lack an informal caregiver who can provide EOL care at home (Gott et al., 2004; Hunt et al., 2014a), or they lack sufficient formal home care supports (Hunt, Shlomo, & Addlington-Hall, 2014b; Stajduhar, 2013; Unroe & Meier, 2013).

Caregivers have significant stress and burden related to caring for ill and dying loved ones at home (Morrison, 2013; Stajduhar, 2013). Spousal caregivers of advanced-age persons, when they exist, are usually older and have health needs of their own (Grande & Keady, 2011). Spousal caregivers report poorer physical health and more psychological distress than adult children caregivers do (Pinquart & Sorensen, 2011). Many adult children, Canada's largest proportion of caregivers, also struggle with balancing other responsibilities such as work as they care for their older parents (Sinha, 2013; Ward-Griffen, 2004; Ward-Griffen et al., 2015). As such, hospitalization may be the family's only recourse to ensure their loved one receives the EOL care needed.

Unfortunately, the quality of EOL care occurring in acute care hospitals for advanced-age adults is often reported as less than ideal (Galanos, Morris, Pieper, Poppe-Ries, & Steinhauser, 2012; Heyland et al., 2005; Hunt et al., 2014a; Lloyd et al., 2016; Lynn et al., 1997; Paice et al., 2004; Teno et al., 2004; Thurston et al., 2011). Overly aggressive treatment, inadequate pain and symptom control, and poor communication are commonly cited issues (Galanos et al., 2012; Hunt et al., 2014a). Communication with older adults and their families about EOL care, terminal prognosis, and decision-making surrounding goals of care is often lacking (Dy, Shugarman, Lorenz, Mularski, & Lynn, 2008; Heyland, Allan, et al., 2009; Heyland et al., 2010a; Huijberts et al., 2016). One study demonstrated that, while the majority of hospitalized advanced-age decedents had a do not resuscitate (DNR) order in place at the time of death (Somogyi-Zalud, Zhong, Lynn, & Hamel, 2000; Thurston et al., 2011), nearly 50% of DNR orders were written within the last 3 days of life (Somogyi-Zalud et al., 2000). This low percentage could reflect late recognition of dying and therefore late planning for the end of life by clinicians.

Moreover, the vast majority of decedents have one or more life-sustaining treatments in use at or near the time of death (Somogyi-Zalud, Zhong, Hamel, & Lynn, 2002; Thurston et al., 2011). One frequently cited US study reported that prior to death in hospital, admissions to a specialty care unit (SCU), such as an intensive care unit or surgical step-down unit, occurred for 54% of patients aged 80+ (Somogyi-Zalud et al., 2000). While some advanced-age adults do require SCU care, the high use of SCU care among decedents 80+ found in Somogyi-Zalud et al.'s (2000) study may not represent advanced-age adult SCU use in Canada.

The humanistic behavioural intentions of the health care professional is also critically important for providing high-quality EOL care (London & Lundstedt, 2007). Good communication builds trust, and relieves stress and anxiety; while poor communication leaves families feeling ignored and forgotten (Stajduhar et al., 2011). Bereaved families have recommended better interpersonal interactions between hospital care providers and families, frank discussions about issues, and improved support for patients informed about a poor prognosis (Bussmann et al., 2015). Moreover, Stajduhar (2013) suggested that caregiver dissatisfaction with the quality of EOL care provided to loved-ones in the hospital was linked with negative outcomes; such as complicated grief, increased use of health services, and caregiver burden. Wilson, Cohen, MacLeod, and Houttekier (2018) also found that the amount of bereavement grief was related to perceptions of the quality of dying; negative perceptions of the quality of dying correlated with higher levels of bereavement grief.

Over the past decade, there has been increased attention to improving the quality of EOL care across Canada (Carstairs, 2005; CHPCA, 2015; Cook & Rocker, 2013; Fowler & Hammer, 2013; Heyland et al., 2005; Heyland, Lavery, Tranmer, Shortt, & Taylor 2000b; Unroe & Meier, 2013; Wenger & Rosenfeld, 2001). Recently, the Canadian Hospice Palliative Care Association (CHPCA, 2015) published *The Way Forward National Framework: A Roadmap to an Integrated Palliative Approach to Care,* a document that outlines key actions to implement an approach to ensure continuity of palliative care across hospitals, homes, and long-term care homes. In addition, the province of Ontario received $75M in 2016 from the Ontario provincial government to improve the delivery of EOL care in the province (Ministry of Health and Long-Term Care, 2016a).

One of several key actions recommended in the National Framework (CHPCA, 2015) was the measuring of patient and family member satisfaction regarding the quality of EOL hospital care received. However, several challenges arise in meeting this action. First, researching perceptions and satisfaction about the quality of care received by individuals who are near the end of life is difficult to do (Lehan Mackin et al., 2009; Merriam, 2002). Dying individuals are often too sick to participate in interviews and surveys, and they are also often not recognized as dying (Addlington-Hall & McPherson, 2001). Bereaved family members instead are often asked to comment on the quality of EOL care (Dy et al., 2008; Wilson et al., 2018). Post-death interviews or surveys of families have been shown to shed much light on best practices and ways to improve EOL care (CHPCA, 2015; Dodek, Heyland, Rocker, & Cook, 2004; McPherson & Addington-Hall, 2003). In addition, post-death studies do not burden dying people with data collection requirements.

Second, few studies measuring satisfaction with care have focused on hospitalized advanced-age adults nearing the end of life or their family's satisfaction (see Mularski et al., 2007). Age is a major research issue; some studies focused on hospitalized adults who were younger (Baker et al., 2000; Heyland et al., 2006; Heyland, Frank et al., 2009). Other studies did not acknowledge or separate age at all (Bussmann et al., 2015; Pierce, 1999). Including people of all ages in a study may be problematic, as there could be much variation between the wishes and needs of younger and advanced-age adults, particularly regarding their preferences for place of death and their access to palliative care supports (Hunt et al., 2014a; Tabloski, 2014; Tanuseputro, Budhwani, Qing Bai, & Wodchis, 2017; Wilson, Cohen, Deliens, Hewitt, & Houttekier, 2013).

Furthermore, some studies have included participants from a number of locations within the hospital; such as intensive care units, cardiac care units, surgery units, and medicine units (Bussmann et al., 2015; Galanos et al., 2012; Heyland, Frank et al., 2009). While overall perceptions regarding EOL care may be highlighted using this approach, differences in perceptions relating to disease trajectory (e.g. sudden decline post-surgery) and resource availability (e.g. varying nursing staff ratios and the availability of social workers) may be overlooked. Using a more homogenous group, such as non-surgical advanced-age adults who died on medical units in hospitals, may reveal valuable quality improvement opportunities that are specific to this location of care and potentially transferrable elsewhere. This research location is appropriate since most deaths of older people will occur on medical units; as admissions to hospital for surgery or for SCU care after an accident has occurred are usually infrequent for this population.

Another issue is that many post-bereavement studies incorporated different types of caregivers, such as spouses and adult children, when evaluating family member perceptions of the quality of EOL care received by their loved one (Heyland, Frank et al., 2009; Ogasawara, Kume, & Andou, 2003; Young, Rogers, Dent, & Addington-Hall, 2009). While the perceptions of all family members and their dying parent are important to understand, adult children may share unique perspectives of the quality of hospital care provided to their advanced-age parent. There is a growing body of research that demonstrates that the caregiving experience and satisfaction with health care services varies depending on culture, education, gender, and stage in one's life course (Bleich, Ozaltin, & Murray, 2009; Footman, Roberts, Mills, Richardson, & McKee, 2013; Giesbrecht, Crooks, Williams, & Hankivsky, 2012; Guberman, Lavoie, Blein, & Olazabal, 2012; Kamra, Singh, & Kumar, 2015). Since most children who have advanced-age parents now are baby boomers, it is likely that this group of individuals will expect higher quality of EOL care than their parents would expect.

Aim and Significance of the Study

There is a need to enhance the knowledge base regarding the quality of hospital care provided to dying advanced-age adults. Despite what is now obviously an out-of-hospital shift, some people, even very old people, will continue to die in hospital. However, few studies have investigated the EOL care provided to persons aged 85+ (CIHI 2007, 2011). Only one dated study examined EOL hospital use in the province of Ontario (Heyland et al., 2000a). A more recent study examined EOL hospital use in all of Canada, excluding Quebec (Wilson et al., 2017). In addition, no study appears to have focused on the perceptions of adult children regarding the EOL hospital care provided to their advanced-age parents. A better understanding of the hospital care provided to dying advanced-age adults can guide quality improvement measures to enhance the quality of EOL hospital care provided to this population. Seeking adult children perceptions about the quality of EOL care provided to their dying advanced-age parent is important because of the growing body of evidence that indicates that variables such as age and gender are linked with satisfaction with health care (Bleich et al., 2009; Footman et al., 2013; Kamra et al., 2015). Moreover, adult children comprise the largest majority of primary caregivers, and these are the persons who often care for their aging parents (Sinha, 2013). The information gained from this study can assist in identifying quality improvement needs, targeting interventions, and helping clinicians to understand the unique perspectives of adult children.

The aim of this study was to develop a substantive theory of high-quality EOL hospital care for non-surgical dying hospital patients aged 85 and older, after establishing population-level socio-demographic and hospital utilization information for this age group. The researcher conducted a two phase mixed methods study that combined the complementary strengths of quantitative and qualitative research methods (Morgan, 1998). This design enhanced the depth and breadth of knowledge gained, while also as expected enhancing descriptions and understanding of issues (Johnson, Onwuegbuzie, & Turner, 2007). This study was designed to answer the research question: What do adult children of parents aged 85 and older consider as high-quality hospital care for their parent during their parent's non-surgical hospital stay that ends in death? The objectives of this study were to: (a) describe advanced-age adults (85+) who die in Ontario acute care hospitals; (b) describe the hospital care provided to advanced-age adults who die in Ontario acute care hospitals; and (c) explore adult children's perceptions about the hospital care received by their parent aged 85+ during the last non-surgical admission that ends in death in Ontario acute care hospitals.

Chapter Summary

Chapter One outlines the background, significance, and aim of this study. Chapter Two presents a literature review surrounding important concepts related to this study. The research methodology is described in Chapter Three. Chapters Four and Five highlight the findings and discussion related to this study. Chapter Six outlines key recommendations and concludes this research report.

CHAPTER TWO

LITERATURE REVIEW

This chapter presents a literature review on quality EOL care for advanced-age adults (85+) who die in hospital. This literature review is presented in two parts. Part 1 highlights five main concepts that helped to plan this study and formulate research questions. The five main concepts are: (a) population growth and aging in Canada, (b) a profile of advanced-age (85+) decedents in Canada, (c) the location of death in Canada, (d) the concept of quality EOL care, and (e) adult children and the influence of respondent variables on perceptions of the quality of health care. Part 2 of the literature review focuses on the known characteristics of dying advanced-age adults (85+) in hospital, the characteristics of hospital use by advanced-age adults who are near the end of life, and known patient and family perceptions of the quality of EOL care received in hospital, with this information presenting the context for the study that was conducted. This chapter concludes with a summary of the current gaps in knowledge regarding quality EOL care in hospital for advanced-age adults.

Part 1 – Background Concepts

The literature review for this study focused on five main concepts, all of which were reviewed in preparation for this study. These concepts enabled the planning of the study, including the designing of the research questions.

Population Growth and Aging in Canada

The number of advanced-age adults in Canada is growing rapidly, with a record high of over 770,780 people aged 85+ registered in the 2016 Census (Statistics Canada, 2017c). According to Statistics Canada (2017c), the percentage of advanced-age adults has increased about four times over the rate of the entire Canadian population between the years of 2011 and

2016. In 2016, one of every eight Canadians aged 65+ was at an advanced age. Those aged 100+, the fastest growing segment in Canada, has grown at a rate of 41.3% (Statistics Canada, 2017c).

In future decades, a continued increase in the advanced-age population is expected because of increasing life expectancy and the aging of the baby boomer cohort (those born 1946 through 1965). Baby boomers will begin to reach 85 in 2031 (Statistics Canada, 2017c). By 2051, twenty years later, when the youngest boomers reach 85, nearly 2.7 million people in Canada and around one in four seniors aged 65+ will be of an advanced age (Statistics Canada, 2017c).

People are also living longer, and despite chronic diseases. In 2015, the life expectancy for men and women in Canada was 80 and 84 years of age respectively (World Health Organization [WHO], 2018). Life expectancy is predicted to continue to increase to 86.6 years for men and 88.7 years for women by the year 2041 (Ontario Ministry of Finance, 2015). Despite this increase in age which implies good health, it is reported that over 50% of older adults now have been diagnosed with three or more chronic conditions (American Geriatrics Society Expert Panel on the Care of Older Adults with Multimorbidity, [AGS], 2012). Such multi-morbidity adds complexity to caring for seriously-ill advanced-age adults (AGS, 2012). The point at which advanced-age adults are really dying is much more difficult to define as compared to younger persons dying of cancer (Gomes et al., 2011; Hall et al., 2011). In a systematic review, Coventry, Grande, Richards, and Todd (2005) found that even the best prognostic models have poor discrimination to accurately predict a less than 6 month survival in non-cancer older adults.

Moreover, the number of people dying in Canada is continuing to rise. Between the 10 fiscal years of 2006-2007 and 2016-2017, the sheer number of deaths has increased from 233,825 to 278,501 (Statistics Canada, 2017a). By 2036, the annual number of deaths in Canada is expected to nearly double (Fowler & Hammer, 2013; Wilson et al., 2017).

A Profile of Advanced-Age Decedents in Canada

In 2016-2017, 99,038 advanced-age (85+) adults died in Canada, comprising 35.6% of all deaths that year in Canada (Statistics Canada, 2017a). Of these, 38.7% were men and 61.3% were women (Statistics Canada, 2017a), with this demonstrating that women typically live longer than men. In 2014, the most recent statistics identifying advanced-age decedent marital status, 64.4% of advanced-age adults were widowed; 27.1% were married; and 3.6% were single, separated, or divorced (Statistics Canada, 2017b).

Advanced-age adults die from a variety of causes. According to Statistics Canada (2017e), in 2014, the most common cause of death for individuals aged 85+ were diseases of the heart (24.3%), malignant neoplasms (16.2%), cardiovascular diseases (7.3%), Alzheimer's disease (4.7%), and chronic lower respiratory diseases (4.7%). Slight differences were seen between men and women; men were more likely to die of chronic lower respiratory diseases (5.5%) and influenza and pneumonia (4.1%), and women had a higher percentage of death as a result of Alzheimer's disease (5.7%) than men (3.1%) (Statistics Canada, 2017e). Differences also occurred between age groups. For example, malignant neoplasms accounted for 45.5% of deaths among decedents aged 65 to 74 as compared to 16.2% of deaths among decedents aged 85+ (Statistics Canada, 2017e).

The cause of death has also been examined by comparing the four trajectories of dying; a concept originally developed by Glaser and Strauss (1968). These are: (a) the sudden death, (b) terminal illness, (c) organ failure, and (d) frailty trajectories of dying (Lunney, Lynn, Foley, Lipson, & Guralnik, 2003). It is argued that different EOL care needs exist for each disease trajectory (Cook & Rocker, 2013; Lunney et al., 2003). Some individuals die suddenly with little warning and interaction from health providers, while others die after a recognizable terminal phase of illness, such as cancer (Lunney, Lynn, & Hogan, 2002). The organ failure trajectory of dying reflects a gradual decline in function punctuated with disease exacerbations that are commonly associated with congestive heart failure and chronic obstructive pulmonary disease (Lunney et al., 2002). Predicting prognosis is much more ambiguous in the organ failure group. The frailty trajectory represents the slow progressive decline commonly associated with frailty, dementia, or stroke (Lunney et al., 2002). Researchers have also criticized the theorized dying trajectories; for instance, Gott et al. (2007) conducted a study of 27 heart failure patients and discovered that only six patients followed the anticipated organ failure trajectory.

Research demonstrates that trajectories of dying are associated with age, cost of health care, location of care, and hospice involvement (CIHI, 2007, 2011; Lunney et al., 2002; Lunney et al., 2003; Tanuseputro et al., 2015; Teno, Weitzen, Fennell, & Mor, 2001). In a US study of 92 older Medicare decedents, Lunney et al. (2002) found that 40% of the terminal illness trajectory decedents died under the age of 75, while 66% of frail decedents were aged 80+. Organ failure decedents had the highest healthcare costs, most often died in hospital, and died between the ages of 75 and 84 (Lunney et al., 2002). Lunney et al. (2003) later found similar age characteristics in a study of 4,190 decedents aged 65+. The terminal illness group represented the youngest group (mean age 78.7 years), followed by the organ failure group (82.3 years), and the frailty group (85.1 years) (Lunney et al., 2003). Teno, Weitzen, et al. (2001) found that non-cancer decedents had a much longer period of functional impairment as compared to those with cancer. A longer period of functional decline was associated with less hospice involvement and dying in a location other than home (Teno, Weitzen, et al., 2001). The organ failure and frailty disease trajectories have also been associated with missed opportunities for goals of care discussions related to clinicians failing to recognize approaching EOL in these populations (Huijberts et al., 2016). In one study, frailty was the most common indicator to initiate a palliative care approach (Gardiner, Gott, Ingleton, & Richards, 2013). Regardless, the four trajectories of dying have been utilized to examine location of death in order to plan better services for EOL care (CIHI, 2007, 2011).

Location of Death in Canada

Evidence suggests that a great majority of older people aged 65 to 85, and just under 50% of individuals aged 85+ would like to die at home (Abarshi et al., 2010; Ahearn, Nidh, Kallat, Adenwala, & Varman, 2013; Verhofstede et al., 2017). However, many deaths continue to occur in hospital (CIHI, 2007, 2011; Hunt et al., 2014a; Wilson et al., 2009; Wilson et al., 2017). While the actual place of death varies across the globe, Canadian statistics show that shifts are occurring (Pivodic et al., 2016; Wilson et al., 2009; Wilson, Hewitt, Thomas, Woytowich, 2014; Wilson et al., 2017). Wilson et al. (2009) found that the proportion of adults 65+ dying in hospital decreased significantly between 1994 (77.7%) and 2004 (60.4%), while deaths occurring in homes and nursing homes increased from 19.3% to 29.5%, and 3.0% to 9.9% respectively. More recently, Wilson et al. (2017) found that only 43.7% of all deaths outside of Quebec occurred in acute care hospitals in Canada in the 2014-2015 year.

Many factors influence the location of death. Factors shown to increase the odds of dying in hospital include living alone and having multiple co-morbidities (Kelley, Ettner, Wenger, & Sarkisian, 2011; Pocock, Ives, Pring, Verne, & Purdy, 2016). Living in a nursing home, advanced age, having a diagnosis of cancer or dementia, and functional dependence were associated with dying elsewhere (Andersson, Hallberg, & Edberg, 2007; Fleming et al., 2010; Gao, Ho, Verne, Glickman, & Higginson, 2013; Kelley et al., 2011; Pivodic et al., 2016; Tanuseputro et al., 2017). Evidence also suggests that advanced-age adults (85+) are more likely to die in long term care homes and less likely to die in hospitals as compared to younger people (Houttekier, Cohen, Pepersack, & Deliens, 2013; Hunt et al., 2014a; Menec, Lix, Nowicki, & Ekuma, 2007). In Manitoba during the year 2000, for example, 56.8% of people aged 65-74 died in hospitals; whereas only 42.9% of people aged 85+ did so (Menec et al., 2007). In contrast, 48.2% of people aged 85+ died in nursing homes (Menec et al., 2007). Advanced-age adults are also less likely to die in hospice as compared to younger people (Gao et al., 2013; Hunt et al., 2014a). Other important determinants of the location of death are factors such as social support, the availability of health care services, and patient needs and preferences (Hunt et al., 2014a; Murray, Fiset, Young, & Kryworuchko, 2009; Wilson et al., 2009; Wilson et al., 2017).

Several studies have investigated factors associated with preferences for location of care (Gott et al., 2004; Hunt et al., 2014a; Wilson et al., 2013). Gott et al. (2004) found that many older people surveyed reported insufficient informal carer support at home. Others did not wish to be a burden to their family, disliked professional care providers coming into their home, or believed that hospitals could provide a better quality of care (Gott et al., 2004). In a survey of Albertans, widowed persons were far more likely to prefer a hospice or hospital as a place of death than married persons (Wilson et al., 2013). In addition, views regarding place of death can change for various reasons as the time of death approaches (Agar et al., 2008; Ahearn et al., 2013). In a study of 71 patient/family caregiver dyads, 24 patients expressed a preference for a home death, but only 9 died at home (Agar et al., 2008). Although 70% of bereaved family caregivers expressed a preference for a home death under ideal circumstances, realistic preferences for a home death decreased from 58% to 49% as death neared (Agar et al., 2008). Unroe and Meier (2013) suggested that even when preferences are known, the lack of community services leave family caregivers unable to support their loved one's wishes.

Studies also identified that patients and caregivers do not always agree on place of death (Agar et al., 2008; Stajduhar, Allan, Cohen, & Heyland, 2008). In a study of 138 patient/family caregiver (FCG) dyads, only 50% of patients and FCGs preferred a home death and only 50% of patients and FCGs agreed on the preferred place of death (Stajduhar et al., 2008). Mismatches between preferred and actual place of death may be a reflection of family needs; one study found that FCGs had a stronger preference for a hospital death and over 90% reported that their relative died in the best place even though the location was not their loved one's preferred place of death (Hunt et al., 2014a; Hunt et al., 2014b).

The trajectory of dying also influences the place of death. In Atlantic Canada provinces during the 2007-2008 fiscal year, the majority of older adults (65+) with terminal illness died in hospital (72.4%), followed closely by those categorized to the organ failure group (66.8%) (CIHI, 2011). Older adults with frailty (48.3%) were the least likely to die in hospital (CIHI, 2011). The terminal illness group (82.4%) also experienced more intensive hospital use ≤ 180 days before death as compared to the organ failure group (66.0%) and the frailty group (47.0%). Moreover, among hospital decedents aged 65+, the terminal illness group (81.7%) were consistently more likely to receive palliative care than the organ-failure group (49.8%) and the frailty group (43.4%). Similar trends were found in Western Canada during the 2003-2004 fiscal year (CIHI, 2007). Unfortunately, these reports did not provide information specific to advanced-age (85+) adult decedents.

Local system factors, such as available hospital beds and skilled nursing homes, have been reported to be stronger determinants for location of death than patient characteristics or patient preferences (Heyland et al., 2000b; Houttikier et al., 2013; Ohta & Kronenfeld, 2011). For example, the availability of special care units and specialized equipment in hospital may increase the chances of patients dying in hospital, especially in urbanized environments (Heyland et al., 2000b; Pivodic et al., 2016).

Together this research suggests that, despite a transition toward home deaths, many older and advanced-age adults will still die in hospital. Advanced-age adults may have unique needs associated with frailty, lack of informal support networks, and decreased access to palliative care supports (Lloyd et al., 2016; Tanuseputro et al., 2017). With the expected rise in the numbers of dying people, there is pressing need to ensure high-quality EOL care is available in the hospital, as well as the community and long-term care facilities.

Quality End-of-Life (EOL) Care

It has been reported that "of hospitalized Canadian elderly, 70% reported wanting comfort measures rather than life-prolonging treatment, but more than two-thirds were admitted to intensive care units" (OHTAC End-of-Life Collaborative, 2014, p. 9). This quote raises serious concerns about neglecting the wishes of dying advanced-age adults. It is imperative that patients and families receive high-quality EOL care in order to experience positive outcomes; such as death in the location of choice, comfort and life completion for patients, and support and better bereavement outcomes for families (Singer, Martin, & Kelner, 1999; Stajduhar et al., 2011; Steinhauser et al., 2000). However, while many authors advocated for better quality EOL care, a clear definition of quality EOL care and the time-line involved has remained elusive (Izumi, Nagae, Sakurai, & Imamura, 2012). Confusion regarding the definition of EOL care and the paucity of conceptual frameworks regarding quality EOL care may have served to impede efforts to assess and improve EOL care in hospitals.

Despite movements to enhance the quality of EOL care in Canada, terms utilized to describe EOL care are often muddied (Izumi et al., 2012). EOL care is used interchangeably with terms such as terminal care and hospice/palliative care (Izumi et al., 2012). Terminal care is sometimes viewed as the last days and hours of life, while hospice or palliative care is often referred to as an approach to care, a specialized service, or the total active care of individuals whose disease is no longer curable (Izumi et al., 2012). EOL care has also been defined as care that is provided in the presence of a chronic, irreversible disease, during a period of 1 to 2 years, or as the comprehensive care that is given in the last hours or days of life (Izumi et al., 2012). It is not surprising then that there is confusion as to when to initiate a palliative care referral (O'Shea, 2014).

Many efforts toward defining quality EOL care stem from the investigation of the outcomes of a good death (Thompson & McClement, 2002). The Institute of Medicine (IOM) defined a good death in 1997 as “one that is free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients’ and families’ wishes; and reasonably consistent with clinical, cultural, and ethical standards” (Committee on Care at the End of Life, IOM, 1997, p. 4). Reflecting the IOM definition, Singer et al. (1999) identified five domains as being important to quality EOL care based on patients’ perspectives. The domains included “receiving adequate pain and symptom management, avoiding inappropriate prolongation of dying, achieving a sense of control, relieving burden, and strengthening relationships with loved ones” (Singer et al., 1999, p. 163). Steinhauser et al. (2000) identified components such as “clear decision-making, preparation for death, completion, contributing to others, and affirmation of the whole person” as contributing to a good death (Steinhauser et al., 2000, p. 825). Other studies described similar themes and domains of quality EOL care (see Table 1) (Ferris et al., 2002; Heyland et al., 2006; Howell & Brazil, 2005; Meier et al., 2016; Nelson et al., 2010; Teno, Casey, Welch, & Edgman-Levitan, 2001). In contrast, Wilson and Hewitt (2017) conducted a scoping literature review to identify factors associated with bad deaths. Factors included physical discomfort, suffering, sudden deaths, prolonged dying, and experiencing disrespect and lack of dignity while dying (Wilson & Hewitt, 2017).

However, how one defines a good (or bad) death depends on one’s perspective. For example, in an analysis of previous literature, Meier et al. (2016) found patients identified religiosity/spirituality more often than family caregivers (FCGs) (65% vs. 50%) as contributing to a good death, while FCGs identified quality of life, dignity, and the presence of family more often than patients did. The top three themes common among patients, families, and HCPs were preferences for the dying process, pain-free status, and emotional well-being (Meier et al., 2016).

Few frameworks were found outlining the concept of quality EOL care. When quality was defined, the term pertained to the quality of a service. For example, the Local Health Integration Networks and the Quality Hospice Palliative Care Coalition of Ontario (2011) defined quality palliative care in terms of access to care and support that is person and caregiver centered; safe, effective, and efficient; adequately resourced; integrated; and available wherever the person was living or dying. Australia and New Zealand indicated, "Quality EOL Care is realized when strong networks exist between Specialist Palliative Care providers, primary generalist providers, primary specialists, support care providers and the community – working together meets the needs of people requiring EOL care" (as cited in ANZSPM, 2014, p. 5.). Elements of palliative care are similar among countries and include bio-psychosocial domains as well as those that pertain to family support, terminal care, and advance care planning (ANSZPM, 2014; CHPCA, 2015; Ferrell et al., 2007).

In this review of the literature, no theory was found that outlined quality of EOL care for advanced-age adults, although several frameworks for other populations were identified. Donabedian's Quality-of-Care model provides a helpful framework to conceptualize quality EOL care (Donabedian, 1988; Mularski, 2006). According to Donabedian (1988), quality of care is organized under the categories of structure, process, and outcomes. Structure refers to the attributes of the setting of care including material and human resources, as well as the characteristics of the organizational structure (Donabedian, 1988). Process refers to the type of care that health care providers provide and how they provide that care (Mularski, 2006). The health care provider's knowledge, skill (technical and interpersonal), and judgement are integral to the category of process (Donabedian, 1988). The outcome category in Donabedian's (1988)

Quality-of-Care model refers to the impact of care on the patient's health, knowledge level, or behaviour. The structure, process, and outcome categories of the Quality-of-Care model are tightly related; good structure promotes good process, and good process promotes good outcomes (Donabedian, 1988). Donabedian (1988) emphasized that relationships between components must be firmly established before assessing the quality of any particular component. To ensure success in enhancing quality EOL care, it is essential that the measured elements of quality EOL care are responsive to quality improvement interventions (Engelberg et al., 2010).

Since 1988, two models have been developed using Donabedian's quality of care framework to identify elements influencing quality EOL care in the intensive care unit (ICU) (Mularski, 2006; Nelson et al., 2010). Mularski (2006) described a theoretical model in which three components influenced the quality of the ICU dying experience. The components included: (a) fixed patient characteristics (e.g. clinical status, patient/rater demographics); (b) modifiable dimensions of care (e.g. symptoms, social support, moment of death); and (c) care system interventions (e.g. preparation for death, aggressiveness of care) (Mularski, 2006). Assessing patient characteristics can highlight risks for a poor quality of dying, while modifiable dimensions of care are targets for goal development (Mularski, 2006). Mularski (2006) asserted that care system interventions are prime targets for quality indicator development and quality improvement measures. Nelson et al. (2010) also outlined important domains relating to high-quality palliative care in the ICU as identified by patients and their families. The important domains included timely and compassionate communication, patient-centered decision making, responsive clinical care of the dying patient, care of the family, and other important care structures and processes that supported high-quality palliative care in the ICU (Nelson et al., 2010).

In addition, in 2011, Stajduhar et al. developed a conceptual framework regarding quality EOL care in hospital after interviewing 24 bereaved family members. Tangible, interpretive, and personal and affective features were found to have influenced satisfaction with EOL care (Stajduhar et al; 2011). Tangible features referred to *"what is (and is not) done," "what is said (and not said)," "how it is done and how it is said,"* and the care environment (Stajduhar et al., 2011, p. 264). The content and method of communication was an example of a tangible feature. Interpretive features referred to issues relating to the health care system and individual provider characteristics, while personal and affective features were the outcomes of care expressed as feelings, relationships, and roles (Stajduhar et al., 2011). Outcomes of care were linked with tangible and interpretive features of care; for example, families indicated that good communication between health care providers and families contributed to a decrease in anxiety and stress, while poor communication resulted in poor bereavement outcomes (Stajduhar et al., 2011).

Most recently, Steinhauser, Voils, Bosworth, and Tulsky (2015) interviewed family members whose loved ones died in hospital to describe the central aspects of the quality of the family's EOL experience. Building on previous work (Steinhauser et al., 2000), the authors confirmed six domains important to the EOL care: (a) "completion," (b) "symptom impact," (c) "relationship with healthcare provider," (d) "decision-making," (e) "preparation," and (f) "affirmation of the whole person" (Steinhauser et al., 2015, p. 948). For example, bereaved family members identified the importance of spending valuable time together (completion), and having clear goals of care (decision-making) (Steinhauser et al., 2015). The authors also identified two new domains as being important to the family; "supportive services" (e.g. open visiting) and "post-death care" (Steinhauser et al., 2015, p. 948).

Several studies assessed staff perceptions regarding components influencing the delivery of quality EOL care. Casey et al. (2011) interviewed staff members in acute care and long-term care facilities in Ireland and identified three key factors that influenced the core component of dying well: (a) the philosophy, culture and organization of the care provided; (b) the physical and environmental resources available; and (c) the sense of knowing the person. A culture of care contributed to dying well when it fostered open communication and support, had adequate resources, and facilitated knowing the person's needs (Casey et al., 2011).

Thompson, McClement, and Daeninck (2006a) conducted a grounded theory study and found that nurses provided optimal EOL care by "creating a haven for safe passage" through the sub-processes of facilitating and maintaining transitions (lane changes), getting what was needed, being present, and manipulating the physical care setting (Thompson et al., 2006a, p. 172). Optimal EOL care occurred when the care team and patient acknowledged that death was approaching, the patient's physical needs were met, and an appropriate care plan was in place (Thompson et al., 2006a). Quality EOL care also occurred when there was time for nurses to be available to patients and families and the physical environment was conducive to a good death (e.g. privacy) (Thompson et al., 2006a).

Acute care nurses have also highlighted factors that influence the provision of quality EOL care. Nurses reported that prognostic uncertainty often delayed transitions toward comfort-focused care (Thompson, McClement, & Daeninck, 2006b). Nurses also reported challenges regarding communication and teamwork (Garner, Goodwin, McSweeney, & Kirchner, 2013; Sheward, Clark, Marshall, & Allan, 2011; Wallerstedt & Andershed, 2007). Poor collaboration and communication with physicians was a strong factor associated with nurses' perceptions of providing futile care (Gagnon & Duggleby, 2014). Nurses reported that the culture of acute care is often treatment focused, with pressures related to "getting people in and getting them out"

(Garner et al., 2013, p. 239). Nurses reported that critical junctures, points in a patient's serious illness where treatment could be re-evaluated, were often not recognized (Willard & Luker, 2006). Health care system constraints, such as high patient acuity, workload issues, rapid patient turnover, and time constraints, were also perceived by many hospital nurses as influencing the quality of EOL care (Bloomer, Endacott, O'Conner, & Cross, 2013; Clarke & Ross, 2005; Garner et al., 2013; O'Shea, 2014; Wallerstedt & Andershed, 2007). Despite the challenges, nurses reported feeling deeply rewarded and privileged to share the EOL journey with dying patients (Gagnon & Duggleby, 2014).

Canada is committed to ensuring quality EOL care (Carstairs, 2005; CHPCA, 2015). Although the identification of quality indicators for palliative and EOL care has received increased attention, most quality indicators were designed to measure the quality of hospice and palliative care provided by palliative care programs (see Dy et al., 2015; Gradwohl & Brant, 2015; Hanson, Scheunemann, Zimmerman, Rokoske, & Schenck, 2010; Weissman, Morrison, & Meier, 2010). However, many measures are transferrable to hospital in-patient units. Quality palliative care indicators commonly measure the structure, process, and outcome metrics associated with the domains of palliative care (e.g. physical, psychological, social, and ethical domains) (Dy et al., 2015; Hanson et al., 2010). Common data sources include administrative, clinical, and patient reported data (Bainbridge & Seow, 2016; Dy et al., 2015). Examples of administrative metrics are length of stay (LOS), 30-day readmission rates, the number of hospital deaths, and the number of emergency room (ER) visits (Bainbridge & Seow, 2016; Cancer Quality Council of Ontario, 2016; Gradwohl & Brant, 2015). Examples of clinical metrics are assessments of pain and symptoms (Bainbridge & Seow, 2016; Dy et al., 2015, Gradwhol & Brant, 2015; Seow et al., 2014). Clinical metrics also include documented discussions with patients and families about treatment preferences, advance-care planning, and the identification of a substitute decision-maker (Bainbridge & Seow, 2016; Dy et al., 2015; Gradwhol & Brant, 2015; Schenck, Rokoske, Durham, Cagle, & Hanson, 2010).

The measurement of quality EOL care also incorporates metrics related to the patient/family experience (Bainbridge & Seow, 2016; Dy et al., 2015; Gradwohl & Brant, 2015; Seow et al., 2016; Seow, Bainbridge, Brouwers, Pond, & Cairney, 2017). Several researchers have conducted interviews with patients and families to enhance quality of EOL care (Hawker et al., 2006; Odgers, Fitzpatrick, Penney, & Wong Shee, 2018; Stajduhar et al., 2011; Steinhauser et al., 2015). Other researchers have used tools such as the CANHELP questionnaire, the FAMCARE-2 scale, or the CaregiverVoice survey to measure patient and/or family satisfaction with EOL care (Aoun, Bird, Kristjanson, & Currow, 2010; Brazil et al., 2013; Frank et al., 2012; Heyland et al., 2010a; Heyland, Jiang, et al., 2013; Sadler et al., 2014; Seow et al., 2016; Seow et al., 2017; You et al., 2014). Although various process and outcome indicators have been suggested, standard palliative care indicators have only recently been published in Ontario (Health Quality Ontario & Ontario Palliative Care Network, 2018).

Over the past few years, several countries have outlined priorities linked to high-quality EOL care of dying people during the last days or hours of life (ANZSPM, 2014; Heyland, 2006; Heyland, 2010a; Lincolnshire Community Health Services NHS Trust, 2015; Marie Curie, 2017). This development comes after mixed reviews of the standardized Liverpool EOL care pathway; a pathway that was reported to overlook the needed individualization of care plans and sometimes cause undue patient and family distress (Leadership Alliance for the Care of Dying People [LACDP], 2014). The Leadership Alliance for Care of Dying People (LACDP, 2014) recommended five priorities of care be instituted when there is concern that death may occur in the next days or hours (Lincolnshire Community Health Services NHS Trust, 2015). The five priorities are: (a) that clinicians recognize the possibility that an individual could die and clearly communicate and make decisions in accordance with patient/family wishes and needs; (b) that staff engage in a timely and sensitive communication with the patient/family, (c) that clinicians involve the dying individual and those important to him/her in treatment and care decisions to the degree the dying individual wishes, (d) that the needs of the individual are actively explored, and (e) that an individualized care plan be created with the patient and those important to him or her (LACDP, 2014). The care plan is tailored to the individual's and family's needs and preferences, is coordinated, and provided with compassion (Lincolnshire Community Health Services NHS Trust, 2015).

Although progress has been made in identifying important components associated with quality EOL care, a firm theoretical foundation is needed to evaluate the quality of EOL care received by hospitalized advanced-age adults. As Donabedian (1988) so aptly wrote many years ago, "To proceed to measurement without a firm foundation of prior agreement on what quality consists in is to court disaster" (p. 1743).

Adult Children and the Influence of Respondent Variables

Little is known about adult children's needs and expectations as they care for advanced-age parents who are near the end of life. The majority of studies on this topic have combined the perspectives of many caregiver relationships, such as spouses and adult children. While each perspective is important, it is expected that similarities and also differences exist. Demographic variables, such as age and education, may influence adult children and spouses' perceptions regarding the quality of EOL care received by their advanced-age family member. Adult children provide a significant amount of caregiving in Canada (Sinha, 2013). As such, adult children may have valuable insights regarding how to improve the EOL care provided to advanced-age adults in hospital; knowledge that could help health care professionals to provide optimal EOL care.

This section of the literature review highlights issues relevant to adult children as caregivers, and reviews demographic variables potentially influencing satisfaction with EOL care.

According to a 2012 General Social Survey, most caregivers (48%) in Canada were adult children who were providing care to their parents or parents-in-law (Sinha, 2013). Most caregivers were between the ages of 45 and 64 (Sinha, 2013). Adult children, many of whom are baby boomers born between 1945 and 1964, may have different expectations of services to help them provide care (Guberman et al., 2012; Moon & Dilworth-Anderson, 2015). Baby boomers are known to stand by their rights and values, seek information, and question previous ways of doing things (Guberman et al., 2012). Unlike their parents who may have lower expectations and ask little, baby boomers tend to express their needs clearly (Guberman et al., 2012). According to Guberman et al. (2012), baby boomers are arriving at an age "when they are key targets of social policy pushing families to care for [their] aging parents" (p. 211). However research suggests that, while babyboomers are willing to be there for their parent, organizing, and overseeing the quality of care that others provide, they expect more help from outside services (Guberman et al., 2012).

Several studies regarding baby boomer caregivers of older adults who had frailty or dementia were examined to understand baby boomer expectations regarding caregiving. Guberman et al. (2006) predicted that future caregivers, especially non-spousal caregivers, will depend on outside supports to provide caregiving duties. In a study of 1,315 baby boomer caregivers of disabled and frail aging relatives, 81% were in total or general agreement with the statement, "It is the duty of family members to take care of their aging relatives" (Guberman et al., 2006, p. 67). The 70+ group expressed higher expectations for family caregiving than younger groups (aged 18 to 30 and 45 to 59) for support activities such as bathing, dressing, and housecleaning. The 70+ group also expressed higher expectations for the family caregiver to move closer to the disabled parent (Guberman et al., 2006). In another study by Guberman et al. (2012), baby boomer caregivers (n = 39) reported they would help their parents but not to the point of self-sacrifice. Instead, they expected more services not only to help maintain their parent in the home, but also for rehabilitation and stimulation. Participants also expected more in compensation both financially and through social supports. Baby boomer caregivers matched the model in which caregivers value individual autonomy and family solidarity, but not to the point of self-sacrifice (Guberman et al., 2012).

Similar to baby boomer caregivers, many adult children are likely to have higher expectations of the quality of EOL care than the expectations of spouses related to variables such as younger age, higher education level, and higher socio-economic status (Bleich et al., 2009). Evidence suggests that these factors are associated with health care system satisfaction (Bleich et al., 2009). According to Urden (2002), satisfaction with health care is influenced by a person's cognitive appraisal of and emotional reaction to the components of care delivery. How events are perceived are based upon the person's experiences, attitudes, and beliefs (Addington-Hall & McPherson, 2001; McPherson & Addington-Hall, 2003). When service and care expectations are not met, satisfaction is lower (Urden, 2002).

Respondent expectations of care are often influenced by various socio-demographic characteristics such as age, gender, education, socio-economic status, and occupation (Bleich et al., 2009; Footman et al., 2013; Kamra et al., 2015). Higher satisfaction levels with health services have been shown to be associated with older age, lower education, and lower socio-economic status (Alturki & Khan, 2013; Bleich et al., 2009; Kamra et al., 2015). Higher levels of self-perceived health status and psychological functioning were also positively associated with perceptions of health care (Bleich et al., 2009; Fakhoury, McCarthy, & Addington-Hall, 1997; Footman et al., 2013). For example, Bleich et al. (2009) conducted a study using a large database from 21 European Union countries to understand determinants of satisfaction with health care and to assess the relationship between satisfaction with the health care system and patient experience. Bleich et al. (2009) found that older adults aged ≥ 70 were more likely to be satisfied with health care than younger individuals aged 18 to 29 ($p < 0.001$). Respondents who reported being in very good health were also likely to be more satisfied with health care than those who had lower ratings of health. Respondents who reported having a negative personality or attitude reported lower ratings of satisfaction. Similar results were found when studies assessed public satisfaction of a health care system in the former Soviet Union (Footman et al., 2013) and a tertiary hospital (Kamra et al., 2015).

Age, cultural background, and relationship to the patient were also factors associated with satisfaction with palliative and EOL care services. Aoun et al. (2010) found that higher satisfaction ratings were reported among caregivers over 50 years of age as compared to younger caregivers in a study testing the reliability of the FAMCARE-2 scale among carers of inpatient palliative care patients. Similarly, in a study evaluating hospital based stroke care in the last three months and three days of life, Young et al. (2009) reported that spouses and partners were 4.27 times more likely to be satisfied with physician care than all other relationship categories. Moreover, Fakhoury et al. (1997) found significant associations between higher satisfaction ratings and better ratings of self-perceived health status and psychological health in a study evaluating bereaved caregivers' satisfaction of palliative care services received by cancer patients. Morita et al., (2004) found similar links between care expectations and depression when evaluating family caregiver satisfaction of the EOL care received on a palliative care unit.

Clearly, there are many factors influencing caregiver responses to evaluations of the quality of health care received. Adult children, due to factors such as younger age and higher education, may have greater expectations regarding the quality of EOL care than do the spouses of dying advanced-age adults. A greater understanding of adult children's perceptions of high-quality EOL care provided to their hospitalized advanced-age parents is needed so that health care providers can anticipate and respond to the family's needs accordingly.

Literature Review – Part 2

Thus far, the literature review identified the need to answer two questions: What is known about the EOL hospital care provided to dying advanced-age adults? and What are adult children perceptions of the quality of the EOL hospital care provided to their dying advanced-age parents? Two literature reviews to answer these questions were conducted to provide a context for the study.

Research on Hospitalized Advanced-Age Adults at the End of Life

To gain a better understanding of what high-quality EOL care is for hospitalized advanced-age adults, a comprehensive search of the MEDLINE and CINAHL databases was conducted using the search terms hospital*, end-of-life, death, terminal*, palliative, older adult*, and aged. The key phrase "dying in hospital" was also used. After reviewing articles and associated key references, 11 research articles were found that provided information specific to the characteristics of hospitalized advanced-age adults (or median/mean age 80+) and the hospital care they received at the end of life. Another article was added after its subsequent publication (Verhofstede et al., 2017). Only five studies provided information regarding hospital use specifically for individuals aged 80 or over who died in hospital (Hesse, 1995; Heyland et al., 2000a; Somogyi-Zalud et al., 2002; Steindal, Ranhoff, Bredal, Sorbye, & Lerdal, 2013; Wilson, 1997). Seven other research studies were reviewed as the mean or median age of the sample was 80 or over (Afzal, Buhagiar, Flood, & Cosgrave, 2009; Ahronheim, Morrison, Baskin, Morris, & Meier, 1996; Esteve, Jimenez, Perez & Gomez, 2009; Formiga et al., 2007; Seah, Low, & Chan, 2005; Twomey, McDowell, & Corcoran, 2007; Verhofstede et al., 2017). Two articles reviewed the same research study (Somogyi-Zalud et al., 2000; Somogyi-Zalud et al., 2002). Studies were conducted in teaching hospitals (n = 5), Geriatric hospital wards (n = 4), and in general hospitals (n = 3). One dated article focused on hospital deaths in Ontario (Heyland et al., 2000a). Fifteen additional articles reviewed EOL care in hospital; however, these studies often included wider age ranges, and the mean or median age of the sample was less than 80 years of age.

Characteristics of hospitalized advanced-age decedents. Studies have demonstrated that the greater proportion of advanced-age decedents were admitted from home, female, widowed (or listed as not married), and had non-cancer diagnoses (Esteve et al., 2009; Steindal et al., 2013; Twomey et al., 2007). In one study, 67% of 50 patients admitted with dementia came from residential care facilities as opposed to 31% admitted with other diagnoses (Afzal et al., 2009). Steindal et al. (2013) also found that fewer advanced-age decedents lived with others as compared to younger decedents (51.1% vs. 70.0%).

The literature reveals a number of common reasons for why advanced-age adults were admitted to hospital: dehydration, infection, pneumonia, heart failure, acute cardiac events, stroke, and pulmonary problems (Esteve et al., 2009; Seah et al., 2005; Somogyi-Zalud et al., 2000; Twomey et al., 2007; Verhofstede et al., 2017). These reasons appear to be similar to Canadian ones (CIHI, 2007, 2011, 2014a).

Characteristics of hospital use by advanced-age decedents. One indicator of poor quality EOL care is the inappropriate prolongation of dying through the use of overly aggressive treatment (CIHI, 2013; Howell & Brazil, 2005; Singer et al., 1999) or the underuse of services such as palliative care (CIHI, 2013). The use of aggressive therapy at the end of life could mean several things; the patient died unexpectedly during therapy aimed at cure or remission, life-sustaining therapy was used despite the remote chance of survival, or that there was lack of clarity regarding the benefits of the therapy (CIHI, 2013). Research has also shown that various factors such as advanced-age, nursing home residence, and having a diagnosis of cancer or Alzheimer's disease were associated with a lower intensity of care at the end of life (Ohta & Kronenfeld, 2011; Tschirhart, Du, & Kelley, 2014). In contrast, an increased intensity of care was associated with factors such as available hospital beds, minority status (Black, Hispanic or Native American), and living in a region with a higher hospital care intensity index (HCI) (Ohta & Kronenfeld, 2011; Tschirhart et al., 2014). The HCI index is a ratio of the average number of hospitalization days that patients spend within a hospital referral region and the number of physician encounters that patients experience during a hospitalization as compared to the national average (Tschirhart et al., 2014).

Life-sustaining interventions usually refer to intensive care unit admissions and high-intensity interventions such as ventilation, cardiopulmonary resuscitation, chemotherapy, dialysis, and tube feeding (Hesse, 1995). Life-sustaining interventions also refer to low-intensity interventions such as blood transfusions, intravenous (IV) therapies, oxygen therapy, and routine blood tests (Hesse, 1995). In the literature reviewed, the presence of a written "Do Not Resuscitate" (DNR) order was also considered an indicator that discussions regarding preferences for care had taken place (Thurston et al., 2011). The characteristics of life-sustaining treatment provided to dying advanced-age adults are summarized in Table 2.

Studies have demonstrated that hospitalized advanced-age adults received a wide variation of life-sustaining treatments near the end of life (Hesse, 1995; Somogyi-Zalud et al., 2002; Steindal et al., 2013; Verhofstede et al., 2017; Wilson, 1997). Somogyi-Zalud et al. (2002) conducted a study within four teaching hospitals in the United States to characterize the use of life-sustaining treatment in hospitalized older persons aged 80+. Among the 72 patients who died during the enrollment hospitalization, 63% had one or more life-sustaining treatments, even though 70% indicated that patients preferred comfort-focused care over the prolongation of life.

In addition, 54% were admitted to an intensive care unit, 43% were placed on ventilators, 18% received cardiopulmonary resuscitation, and 18% had tube feeds (Somogyi-Zalud et al., 2002). Of the patients (80+) who died during the enrollment hospitalization, 81% had a DNR order in place at some point prior to death (Somogyi-Zalud et al., 2002).

In contrast to Somogyi-Zalud et al.'s (2002) US study, other studies found lower proportions of ICU admissions and/or deaths among advanced-age decedents (Hesse, 1995; Heyland et al., 2000a; Steindal et al., 2013; Wilson, 1997). Hesse (1995) found that admissions to ICU occurred in 21.6% of advanced-age patients at some point during the terminal hospitalization, and 12.0% and 14.3% of advanced-age patients died in ICU in 1988 and 1993 respectively. Although Hesse (1995) found no observed differences in the patterns of ICU usage and high and low-intensity interventions that were provided to decedents 85+ before and after the implementation of the 1990 Patient Self-Determination Act, the study found that DNR orders were written earlier and CPR was provided less often to very-old patients after the Act was implemented.

Steindal et al. (2013) studied the differences between nurses documentation of young-old (aged 65 – 84) and the oldest-old patients (aged 85+) with regards to the symptoms these patients experienced and the treatments these patients received during the last three days of life in a Norway hospital. Although no significant differences in treatment were found between these two age groups, only 10.1% of the oldest-old patients were admitted to intensive care units and 10.1% of the oldest-old patients received mechanical ventilation there (Steindal et al., 2013). However, a great majority of oldest-old received low-intensity interventions such as IV medications (84.3%) and/or oxygen (78.7%) within the last three days of life, while a small proportion underwent suctioning (11.2%) (Steindal et al., 2013).

The results presented in Canadian studies conducted by Wilson (1997) and Heyland et al. (2000a) allowed for calculations for comparing hospital use among young-old (aged 65 – 84) and old-old (aged 85+) patients. In contrast to Steindal et al.'s (2013) study, Wilson (1997) found that patients aged 85+ were much less likely to be admitted to ICU than younger patients (7.7% vs. 25.0%) and less likely to receive IV therapy (41.0% vs. 73.2%). As in Steindal et al.'s (2013) study, Wilson (1997) found no difference in the use of feeding tubes and oxygen use between all age groups. In a study of hospital deaths in Ontario during the year 1997, Heyland et al. (2000a) reported that 77% (n = 30806) of all hospital deaths occurred among individuals aged 65+. Calculations indicated that 12.9% (n = 3,980) of special care unit (SCU) deaths occurred in the young-old group and 2.0% (n = 624) of SCU deaths occurred in the old-old group; a distinct contrast to the 54% of advanced-age decedents admitted to ICU in Somogyi-Zalud et al.'s (2002) study.

Three studies compared the treatment received by patients who had advanced dementia to those who had non-dementia diagnoses, metastatic cancer, or heart failure (Afzal et al., 2009; Ahronheim et al., 1996; Formiga et al., 2007). Although these studies found that patients with dementia were significantly older as compared to patients without dementia, cancer, or heart failure, no difference was found between these groups in relation to the presence of DNR orders or ICU admissions (Afzal et al., 2009; Ahronheim et al., 1996; Formiga et al., 2007). However, Afzal et al. (2009) found that dementia patients were less likely to be referred to palliative care services (22.2% vs. 62.5%) and were less likely to have caregivers involved in treatment decisions (50.0% vs. 87.5%) than patients without dementia. Afzal et al. (2009) found that, during their last hospitalization ending in death, a great majority of dementia and non-dementia patients were subjected to arterial blood gas draws (83.3 % vs. 84.4%) and phlebotomy (88.9% vs. 90.6%), and about one-third of patients had mechanical ventilation (33.3% vs. 28.1%) and nasogastric tube insertion (33.3% vs. 34.4%). Slightly over half of patients had resuscitation decisions in place (55.6% vs. 59.4%).

Similar to Afzal et al. (2009), Ahronheim et al. (1996) found that patients with advanced dementia and metastatic cancer were equally likely to receive invasive non-palliative treatments such as hemodialysis, central venous access line, and mechanical ventilation. There was also no statistical difference in the documentation of a DNR order between the two groups (75% dementia vs. 82% cancer). However, Ahronheim et al. (1996) found patients with dementia more often had tube feedings on admission to hospital than patients with cancer and were more likely to have new enteral feeding tubes placed as compared to patients with cancer. The authors attributed higher enteral feeding use in patients with dementia to the potential influences of state law standards; higher standards pertained to the withholding and withdrawal of enteral feeding as compared to other life-prolonging therapies.

Four studies examined the EOL care that was provided to patients on acute geriatric care wards and had sample mean or median ages of 80 or over (Esteve et al., 2009; Seah et al., 2005; Twomey et al., 2007; Verhofstede et al., 2017). Seah et al. (2005) found high rates of high-intensity interventions among elderly persons who died on geriatric wards in Singapore. For example, although death was expected in 88% of cases of elderly decedents, 25% of these persons received CPR, and 17% were intubated at the time of collapse (Seah et al., 2005). Treatments such as IV medications (96%) and nasogastric tube feeds (46%) were also prevalent in patients whose death was expected (Seah et al., 2005). Elderly patients who were referred to palliative care services were more likely to have greater degrees of functional dependence and were less likely to undergo resuscitation attempts than those who were not referred to palliative care (Seah et al., 2005).

Esteve et al. (2009) and Twomey et al. (2007) found similar rates of DNR documentation among patients on elder care units (83.3% vs. 84.0%). Moreover, Esteve et al. (2009) found that patients with American National Hospice and Palliative Care Association (NHPCO) criteria were also more likely to have a DNR order in place prior to death than those without NHPCO criteria. Patients with NHPCO criteria also had significantly greater functional impairment, cognitive impairment, and co-morbidity prior to admission than patients without NHPCO criteria (Esteve et al., 2009).

Consistent with other studies, Verhofstede et al. (2017) found that the most common medical interventions in the last 48 hours of life among patients who died on geriatric wards in Belgium were oxygen therapy (49.7%), IV fluids (30.0%), antibiotics (22.8%), and routine blood tests (19.2%). Moreover, the most frequently reported comfort issues that families reported as occurring “a lot” were shortness of breath (45.1%), restlessness (34.3%), anxiety (25.8%), and pain (23.7%) (Verhofstede et al., 2017, p.698). Pain and dyspnea were also commonly reported symptoms in other studies examining EOL care in the advanced-age population (Formiga et al., 2007; Seah et al., 2005; Steindal et al., 2013; Twomey et al., 2007).

It is difficult to draw conclusions then that are based on the studies that described treatments received by advanced-age decedents in hospital. Studies had different inclusion criteria based on age and unit within the hospital. Only five provided information specifically on patients aged 80+ (Heyland et al., 2000a; Hesse, 1995; Somogyi-Zalud et al., 2000; Steindal et al., 2013; Wilson, 1997). Studies often investigated different treatments and used different treatment timelines. For example, some studies examined treatments and procedures performed within three days prior to death, while others included the entire hospital stay. Most studies reported the presence of a DNR order in almost 80% or more of cases (Ahronheim et al., 1996; Somogyi-Zalud et al., 2002; Twomey et al., 2007). Only Somogyi-Zalud et al.’s (2002) US study showed surprisingly high ICU admission rates among advanced-age adults (80+). The difference may relate to the fact that this study occurred in four US teaching hospitals.

These studies revealed mixed results regarding the use of enteral tube feeding when patients with dementia were compared to those without dementia. Afzal et al.'s (2009) finding that dementia patients receive less palliative care referrals as compared to non-dementia patients is disturbing as many studies found pain and dyspnea to be two of the most prevalent symptoms experienced by advanced-age adults at end of life (Formiga et al., 2007; Seah et al., 2005; Steindal et al., 2013; Twomey et al., 2007; Verhofstede et al., 2017).

Several studies regarding hospital use and treatment received at the end of life for younger patients were also reviewed (Table 3). Mean or median ages ranged from 61.4 to 77.1 (Nadimi & Currow, 2001; Toscani et al., 2005). As expected, studies generally reported greater proportions of ICU/SCU and ventilator use when ages were younger. Eight studies reported ICU admissions for 27% or more of decedents with the highest reporting 80.1% (Becker et al., 2007; Dendaas, Pellina, Roberts, & Cleary, 2001; Fins et al., 1999; Moyano, Zambrano, & Mayungo, 2010; Nadimi & Currow, 2011; Ohta & Kronenfeld, 2011; SUPPORT Investigators, 1995; Wilson, 1997). Studies undertaken within large teaching hospitals also reported higher ventilator use (range 45.7 – 53.1%) (Becker et al., 2007; Fins et al., 1999).

Patient and Family Perceptions of Hospital Care at the End of Life

To determine adult children perceptions of hospital care received by their advanced-age parent (80+) during the last non-surgical admission ending in death, the researcher conducted another focused comprehensive review of literature. Searches were conducted utilizing four databases (MEDLINE, PsycINFO, CINAHL, and EMBASE) and search terms relating to EOL care for advanced-age adults (dying, death, end-of-life, terminal, or palliative care; hospital* or inpatient*; aged, elder*, older adult*, older people, older person*, or older patient*; and satisfaction, view*, opinion*, or perception*). The inclusion criteria were adult children caregivers, parent over the age of 80, and the parent's death occurred in hospital during a non-surgical admission. The literature search excluded studies that examined deaths that occurred primarily in the palliative care unit or hospice, intensive care, or emergency room setting. No articles matched the inclusion and exclusion criteria. Furthermore, only one article focused exclusively on decedents over the age of 80 (Bravell, Malmberg, & Berg, 2010), and only three articles examined patient or family perceptions of EOL care on medical and geriatric in-patient units (Formiga et al., 2007; Heyland, Barwich et al., 2013; Natan et al., 2010). These findings are surprising given that over 50% of deaths in Canada in the year 2014 occurred among individuals aged 80+ (Statistics Canada, 2017d) and that 80% of deaths in hospital occurred on general medical/surgical wards (Heyland et al., 2000b). This presents a serious gap in knowledge.

To examine the present knowledge of patient and family perceptions regarding the quality of EOL care provided to hospitalized older adults in general, studies presenting a mean or median patient/decedent age of 75+ were examined. The review excluded articles that focused mainly on hospice, palliative care units, emergency room visits, or intensive care units. In total, the literature search located 20 articles. Studies often spanned different caregiver age groups, patient ages, and settings within the same study. Researchers also used various tools to measure the quality of EOL care. Despite these limitations, the following section presents what is known about patient and family perceptions of EOL care in hospital for older adults with a study mean or median age of 75+.

Qualitative research findings. In addition to 14 quantitative studies, 6 qualitative research articles reviewed patient and/or family perceptions of the quality of EOL care in hospital. Table 4 summarizes qualitative findings. Donobedian's Quality-of-Care model (1988) was used to theme findings of the qualitative studies under the categories of structure, process, and outcome. Several studies identified structural elements within the hospital system as being important to quality EOL care. Donnelly and Battley (2010) conducted a qualitative analysis with 24 family members of 15 deceased patients to explore how families experienced the moment of death in a hospital in Ireland. Two of the four themes that researchers identified were hospital as a place to die and location within the hospital. Families were critical of the cleanliness of the room, the restrictive visiting hours at night, and the difficulty they had parking when hurrying to visit their loved one near the moment of death. Noise, cramped spaces, and having to find a public bathroom on a different floor added to family distress. Some families preferred a private room, while others were content to draw the curtain for privacy. Hawker et al. (2006) and Payne et al. (2007) identified similar themes when examining the nature and quality of EOL care in community hospitals. In addition to the clean, comfortable environments community hospitals offered, the location of the hospital enhanced the ease of visiting for families (Hawker et al., 2006; Payne et al., 2007). Payne et al. (2007) interviewed 18 patients and 11 family caregivers regarding EOL care in community hospitals. Patients revealed community hospitals were more responsive to their needs and not as geographically distant as compared to larger hospitals. The patients' preference for a private room also varied. Many families preferred private rooms, but these rooms were often in high demand in small hospitals (Payne et al., 2007).

Stajduhar et al. (2011) identified tangible, interpretive, and personal affective features relating to quality EOL care in hospital. Structural elements relating to the health care system included procedural wait times, staffing levels, staffing turnover, and families' perception of the busy-ness of staff. Family members often perceived staff as being hard to track down or understandably busy given their workload (Stajduhar et al., 2011).

Important process elements relating to the role of health care providers in EOL care included communication with the patient and family, direct physical care of the patient, and emotional care of patients and families (Donnelly & Battley, 2010; Jacobs, Bonuck, Burton, & Mulvihill, 2002; Stajduhar et al., 2011). Process elements included the family's role as advocates as they assisted with care decisions. Jacobs et al. (2002) conducted an institutional assessment regarding EOL care practices through focus groups, chart reviews, and interviews with bereaved family members regarding the care of 30 patients who died in ICU and 30 patients who died on a geriatric unit. Family members indicated that the quality of communication with health care professionals was extremely important; families wanted to be kept informed about their loved one's condition and have regular communication with the health care team (Jacobs et al., 2002). Inadequate communication and information about the patient's condition limited the family's ability to participate actively in treatment decisions (Jacobs et al., 2002). Families also wanted to be informed in direct terms regarding their loved one's terminal diagnoses and know what to expect (Stajduhar et al., 2011). Fifty percent of family members in Jacobs et al.'s (2002) study were not aware of the impending death of their loved one until the final week of life. Several family members in Hawker et al.'s (2006) study also raised concerns about not being prepared for their loved one's death. As a result, some family members were upset that they were not able to be with their loved one at the time of death (Hawker et al., 2006).

Bereaved family members valued good patient care (Jacobs et al., 2002; Stajduhar et al., 2011). Good patient care included personal care, pain and symptom management, appropriate treatments, and psychosocial/emotional support (Stajduhar et al., 2011). Bereaved families members also valued pain relief more than extending their loved one's life (Jacobs et al., 2002). Although most family members in Jacobs et al.'s (2002) study reported satisfaction with the physical care of their loved one, 27% of family members reported that excessive measures and testing were done to keep their loved one alive. Families desired more communication, especially from physicians, so they could be more actively involved in the decision-making process (Jacobs et al., 2002).

James, Andershed, and Ternestedt (2009) conducted a qualitative study of 27 caregivers whose family members died in a Swedish university hospital to understand caregivers' experiences of informal and professional caregiver encounters in hospital. The study found that family carers often struggled to see that their loved one obtained the right treatment and care, and they acted as experts and protectors for their family member. They reported a lack of confidence in the knowledge of professional carers relating to their concerns about inadequate pain control, nourishment, and fluid provision. James et al. (2009) also identified that family caregivers demonstrated a specific type of knowledge; family caregivers had a "moral deliberation concerning which actions are best, or least harmful, when it comes to helping another human being" (p. 267). Families knew their loved ones, advocated and protected them, and expected respect from health care providers as knowledgeable caregivers (James et al., 2009).

The process of how care was given referred to the mannerisms and behaviours of health care providers as they provided care and communicated with the patient and family (Stajduhar et al., 2011). Positive staff attributes, such as skill, humanity, and providing dignified care to patients, developed a sense of trust in family members (Donnelly & Battley, 2010). Some patients reported that community hospitals had kind and caring nurses, but nurses were sometimes perceived as being less qualified as compared to nurses in larger hospitals (Payne et al., 2007). Family members reported dissatisfaction when health care providers focused primarily on tasks rather than on communication and when staff behaviors were condescending or annoying (Stajduhar et al., 2011). Family members appreciated being valued as patient advocates (Donnelly & Battley, 2010).

Outcomes of EOL care included the reactions of patients and family members (Stajduhar et al., 2011). Good care promoted confidence, trust, and appreciation among family members; as families felt cared about (Stajduhar et al., 2011). Inadequate care generated anxiety, anger, regret, or distress (Stajduhar et al., 2011). In addition, positive environments promoted a sense of calmness and emotional comfort among family members, while poor environments generated distress (Stajduhar et al., 2011).

Quantitative published research findings. Fourteen quantitative research studies highlighted EOL hospital care as perceived by patients and/or families (see Table 5). Studies reported mean patient/decedent ages ranging from 75.1 to 92.5, while other studies reported percentages of decedents over 75 (Bravell et al., 2010; Sadler et al., 2014). The percentage of adult children respondents ranged from 33% to 80.5% (Bravell et al., 2010; Brazil et al., 2013). Studies reviewed the quality of care received by inpatients who died from stroke ($n = 2$) and cancer ($n = 2$). Studies also reviewed the quality of care provided to patients who died on geriatric units ($n = 2$) and the internal medicine departments of teaching hospitals ($n = 2$). Three studies examined aspects related to communication, decision-making, and advance care planning (Brazil et al., 2013; Heyland, Barwich et al., 2013; You et al., 2014), and one study examined patient and institutional factors associated with EOL care (Sadler et al., 2014). The latter four articles occurred within various units of the hospital including the ICU. As mentioned previously, the knowledge base for EOL care for hospitalized advanced-age adults is limited.

Quantitative studies evaluated elements such as the overall hospital care provided, the hospital environment, the care of the patient, symptom management, communication and decision-making, and preferred location of care. Natan et al. (2010) surveyed geriatric inpatients, family members, nurses, and physicians to compare perspectives of patient needs at the end of life. The researchers found five needs to be most significant for all groups: (a) freedom from pain, (b) maintenance of dignity, (c) having attentive staff, (d) feeling comfortable with nursing staff, and (e) preventing respiratory difficulties. Older patients were not interested in life prolonging measures when there was no cure. The vast majority (86.4%) of patients reported that they would want the truth regarding their prognosis, and 57% reported they would want to die at home (Natan et al., 2010). According to Natan et al. (2010), older patients also valued maintaining hygiene, receiving regular updates regarding their medical condition, having opportunities to discuss their fears and anxieties, and being involved in care policies and decisions. Family members valued receiving updates on their loved one's condition, having opportunities to discuss fears, and being involved in patient policy and care decisions. Differences between patient and family groups were also apparent. Patients placed significantly more importance on such items as remaining conscious, telling the truth, and discussing fears than doctors and nurses did. Family members placed more importance than physicians and nurses on updating patients and families (Natan et al., 2010).

Overall, hospital care was generally rated as good or excellent by bereaved family members in Italian and Swedish studies (Beccaro, Caraceni, Costantini, & ISDOC Study Group, 2009; Bravell et al., 2010), but slightly less so on internal medicine wards in Barcelona (66.5%) (Formiga et al., 2007). Bravell et al. (2010) conducted a study of 102 randomly selected bereaved family members to describe the last year of life in the oldest-old (aged 86, 90, and 94) in Sweden. The majority of respondents rated staff attitudes and treatment, and staff competence as very good (47% and 52% of the time respectively) (Bravell et al., 2010). In a study investigating the quality of care received by stroke patients in the last year of life, proxies rated nursing care excellent almost half the time (46%), while 29% rated doctors' care as excellent (Addington-Hall, Lay, Altmann, & McCarthy, 1995). Perceptions of nursing care also varied depending on the location of EOL care. In a study of the last three months of cancer care, excellent ratings regarding nursing care were significantly higher in hospices (83.3%) as compared hospitals (38.9%) (Addington-Hall & O'Callaghan, 2009).

Bereaved families commonly reported a lack of privacy in hospitals (Addington-Hall et al., 1995; Formiga et al., 2007). Yet, proxies of stroke patients reported that rooms were peaceful and quiet in 43% of cases, and 57% of patients were satisfied with the amount of privacy they received; however, 27% indicated their loved one had no privacy at all (Addington-Hall et al., 1995). Families recommended the availability of more single rooms (Formiga et al., 2007).

Patients experienced a variety of often poorly controlled symptoms (Beccaro et al., 2009; Formiga et al., 2007). Formiga et al. (2007) surveyed bereaved caregivers of decedents who had dementia and heart failure to evaluate the circumstances of death on internal medicine departments of two teaching hospitals. Caregivers reported that symptoms were controlled in only 55% of dementia and heart failure decedents; 13.5% of decedents were reported to have uncontrolled pain and 45% had uncontrolled dyspnea (Formiga et al., 2007). Similarly, in a study evaluating care provided to dying cancer patients in Italian hospitals, bereaved family members reported their loved ones experienced very distressing symptoms, including pain, nausea and vomiting, and dyspnea (Beccaro et al., 2009).

The communication and provision of information was often reported as fair to poor (Beccaro et al., 2009; Heyland, Barwich et al., 2013; You et al., 2014). You et al. (2014) conducted a study among 233 hospitalized patients with serious illness and 205 family members to determine key elements that were most important to them in discussions regarding goals of care and to assess how frequently hospital charts reflected patient and family goals of care. Patients and family members rated the following elements of EOL care discussions as most important: (a) being asked about care preferences and values, (b) discussing prognosis, (c) being able to communicate their fears and concerns, and (d) asking if they had any other questions (You et al., 2014). You et al. (2014) reported that patient preferences and documented hospital care matched in only 29.7% of cases, while family preferences and hospital care matched in only 35.6% of cases. EOL care satisfaction scores, as measured by the Canadian Health Care Evaluation Project (CANHELP) questionnaire, were higher in patients who had a greater number of care elements discussed (You et al., 2014). Similarly, Heyland, Barwich et al. (2013) interviewed seriously-ill patients and their family members to determine whether advance care planning and preferences of care pre-hospital admission matched with chart documentation. Researchers found only a 30.2% agreement between patients previously stated care preferences and chart documentation.

Two studies reported satisfactory information sharing between bereaved family members and health care providers near the end of life (Brazil et al., 2013; Formiga et al., 2007). Brazil et al. (2013) surveyed 250 bereaved families of seriously-ill patients to evaluate satisfaction with communication and information sharing and to determine how patient factors are associated with such satisfaction. Family members rated overall satisfaction with information sharing at 3.9 on a 5-point Likert scale (5 = completely satisfied) (Brazil et al., 2013). Lower satisfaction scores were associated with items such as sharing information about the adverse effects of treatment, providing information about how to manage patient symptoms, and the timing of end of life discussions; while higher satisfaction scores were associated with how care providers worked as a team and followed patient wishes (Brazil et al., 2013). Longer hospital stays and male gender were associated with lower satisfaction scores, while higher scores were associated with receiving care in the ICU (Brazil et al., 2013). Formiga et al. (2007) reported that 67.6% of caregivers were satisfied with the information received; however caregivers still requested better communication.

Two interventional studies demonstrated that patient and family satisfaction increases when providers attend to patient/family needs and preferences (Detering, Hancock, Reade, & Silvester, 2010; Frank et al., 2012). Frank et al. (2012) evaluated a nurse facilitator-led quality improvement project on an inpatient medical teaching unit. In a small cohort of seriously-ill patients (n = 37), discrepancies between areas of satisfaction with EOL care and areas of importance were identified using the CANHELP patient questionnaire. Researchers then developed strategies to address gaps. In the second cohort of patients (n = 34), a pre-intervention and a two week post-discharge satisfaction survey was distributed. The intervention involved a nurse-facilitator working with the health care team to address individualized inpatient needs using a standardized form. A significant improvement was reported in all 10 priority areas; however, specific details were not provided about this in the published article (Frank et al., 2012).

Detering et al. (2010) conducted a randomized control trial to assess the impact of an advanced care planning intervention. Trained facilitators held sessions with patients and families in the intervention group to reflect upon their values, goals, and care preferences, while the control group received usual care (Detering et al., 2010). The researchers found that families in the intervention group reported greater satisfaction with care and less stress, anxiety, and depression than the control group. Patients in the intervention group were also more likely to have their wishes known and followed than patients in the control group (Detering et al., 2010).

Four studies reported elements that best predicted overall satisfaction with EOL care (Beccaro et al., 2009; Sadler et al., 2014; You et al., 2014; Young et al., 2009). Variables best predicting overall family satisfaction with EOL care provided to stroke patients included the following: (a) the availability of personal and nursing care for the decedent, (b) family member involvement in treatment and care decisions as much as they wanted, and (c) family belief that the death occurred in the right place (Young et al., 2009). Variables best predicting overall satisfaction regarding care received from doctors and nurses included: (a) the ability of the family member to discuss worries and fears regarding the patient's condition, treatment, or investigations, and (b) having confidence that doctors and nurses had sufficient knowledge regarding the patient's condition (Young et al., 2009). Similarly, the probability of satisfaction for bereaved families of cancer patients increased when doctors provided information regarding treatment, the patient's condition, and impending death (Beccaro et al., 2009).

Location of care was also a factor influencing family satisfaction with EOL care. Sadler et al. (2014) conducted a study in a Toronto hospital to investigate institutional factors associated with quality EOL care. Bereaved family members who believed their loved one died in the right location were 1.9 times more likely to be satisfied with the quality of EOL care (Sadler et al., 2014). Heyland et al. (2010a) identified high priorities for EOL care improvement as perceived by hospitalized patients with life-limiting illness and their families. Areas for improvements common to both included enhanced emotional support for families and better communication with doctors (i.e. availability, listening to needs, receiving timely updates, consistent information, and receiving information about location of care choices and life-sustaining technologies) (Heyland et al., 2010a).

Chapter Summary

This chapter presented a literature review to identify and describe the main concepts for this study and also the results of two focused literature reviews. In summary, of the focused literature reviews, patients and families generally reported satisfaction with EOL hospital care; however, improvements were needed. Themes reviewed in qualitative and quantitative studies included communication, information sharing, and decision-making. Families commented on the busy culture of hospital care and provided suggestions to improve the hospital environment (e.g. privacy, cleanliness). Communication between health care providers and family was a key aspect associated with quality EOL care. Many families asked for more information regarding condition, and several reported being taken off guard when their family member died, seemingly unexpectedly.

Several evidence gaps were also identified in the literature review. Although there is evidence that the numbers of advanced-age adults dying in Canada are continuing to rise, there is a paucity of literature describing the EOL care received by hospitalized advanced-age adults and of family perceptions related to the quality of EOL care received in hospital. Studies often combined information for advanced-age adults with younger age groups. Furthermore, no study was found that focused on adult children perceptions of the quality of EOL care received by their parent. While perceptions of all family caregivers are important, adult children are likely to provide unique perspectives on the quality of EOL care received by their advanced-age parents. Equipped with knowledge about adult children's perceptions, health care professionals can more effectively tailor their interventions to meet the needs of the patient and their family. Therefore, the purpose of this study was designed specifically to develop a substantive theory of high-quality EOL hospital care for non-surgical patients aged 85 + who died in hospital based on adult children perceptions. The objectives of this study were to: (a) describe older people (aged 85+) who died in hospital, (b) describe the health care provided in hospital to older persons aged 85+ who died in hospital, and (c) explore adult children's perceptions about the quality of hospital care received by their parent aged 85+ during the last non-surgical admission that ended in death.

.

Table 1

Themes related to Quality End-of-Life Care: Patient/family perspectives

Citation	Singer et al. (1999, p.165-167)	Steinhauser, et al. (2000, p. 825-832)	Teno, Casey, Welch, and Edgman-Levitan (2001, p. 742-743)	Heyland et al. (2006, p. 5-9)	Nelson et al. (2010, p. 813)	Howell and Brazil (2005, p. 22-23)
Design	Qualitative; interviews	Qualitative; focus groups, 1:1 interviews	Qualitative; Focus groups	Quantitative; Questionnaire	Qualitative; Focus groups	Meta-synthesis
Sample	Patients on dialysis, with human immunodeficiency virus, and residents of long term care (n = 126)	Bereaved family members, patients, health care providers, hospice volunteers (n = 100)	Bereaved family members from acute care hospitals, nursing homes, home care (n = 42)	In-patients aged 55+ with serious illness, and aged 80+ (n = 434), or their family members (n = 160)	Patients who survived the ICU Families of survivors, families of deceased (n = 48)	Qualitative studies focusing on patient/family perspectives in adult populations (n = 7 studies)
Themes	“Receiving adequate pain control”	Adequate pain/symptom management	Provision of physical comfort	Symptom relief	Clinical care of dying patient: comfort, dignity, personhood, privacy	Adequate pain and symptom control Whole person/ individualized care
	“Achieving a sense of control”	“Affirmation of the whole person” “Clear decision-making”	Achieving control over daily decisions and sharing control over treatment decisions	Avoidance of unwanted life support	Patient-centered decision-making	Not prolonging dying process
				Communication with physician	Timely communication by clinicians	Providing decision-making support
		“Preparation for death”	Providing family with emotional support before and after the loved one’s death		Providing family care: access and proximity to patient, and supportive care	Being prepared for death
	“Relieving burden”	“Contributing to others”	Decreasing the family’s need to advocate for quality of care	Trust and confidence in physicians	Important care processes & structural aspects of quality EOL care in ICU	Having support of family and friends
	“Strengthening relationships with loved ones”	“Completion”	Educates the family and increases their confidence to care for loved ones at home	Life completion including life review, resolving conflicts, and saying goodbye		Death occurring in a supportive environment in desired location Spiritual support/ meaning-making

Table 2

Hospital Use and Symptoms Experienced by Advanced-age Adults (and samples with mean/median ages 80+)

Citation	Hospital Type: Place; Focus	Sample $N^{Timeframe}$	Age of Death (Mean ± SD)	Selected Interventions Prior to Death %					Symptoms %	
				ICU/SCU	Ventilator	FT/NG	DNR††	CPR	Pain	Dyspnea
Afzal et al. (2009)	Major teaching hospital: Dublin; Internal Medicine unit deaths 65 + (Dementia: Non-dementia)	50^{LH} (18 D: 32 ND)	83± 8 D 77± 9 ND	---	33.3 D: 28.1 ND	33.3 D 34.4 ND	55.6 D 59.4 ND	---	---	---
Ahronhein et al. (1996)	Large teaching hospital: New York; deaths 65+ with advanced dementia, metastatic cancer	164^{LH} (80 D; 84 C)	(36.0 % ≥ 85) D: 61.3 % ≥ 85 C: 11.9% ≥ 85	---	18 D 14 C	26.0 D 9.5 C*	75.0 D 82.0 C	24 D 24 C	---	---
Esteve et al. (2009)	Inner-city hospital: Spain; elderly acute care unit deaths	90^{LH}	86.5± 6.6	---	---	---	83.3	---	---	---
Formiga et al. (2007)	Two tertiary teaching hospitals: Spain; Internal Medicine Department deaths 65+	102 (37 D; 65 HF)	87.2 ± 7.6 D* 81.4 ± 7.6 HF	3 D $^{Last\ 5\ yrs}$ 5 HF$^{Last\ 5\ yrs}$	---	---	81 D 94 HF	3 D 5 HF	13.5 D 14.0 HF	51.5 D 41.5 HF
Hesse (1995)	Community teaching hospital, USA; deaths 80+	83 $(1988)^{LH}$ 84 $(1993)^{LH}$	89.8 (1988) 90.1 (1993)	12.0 (1988) 14.3 (1993)	8.4 (1988) 3.6 (1993)	18.1 (1988) 10.7 (1993)	95.8	12.0 (1988) 3.6 (1993)	---	---
Heyland et al. (2000a)**	Ontario Hospitals CIHI (65+ deaths = 77% of n = 40,008)	$30806^{\dagger\dagger}$	---	12.9 YO 2.0 OO	---	---	---	---	---	---
Seah, Low, and Chan (2005)	Acute Care Hospital: Singapore; deaths 75+	$189^{30d\ BD}$	84	---	---	50	---	---	31	59
Steindal et al. (2013)	General Hospital: Norway; deaths 65+	$190^{3d\ BD}$ (101 YO; 89 OO)	79† YO 89† OO	12.9 YO 10.1 OO	7.9 YO‡ 10.1 OO‡	---	---	---	73.3 YO 70.8 OO	74.3 YO 77.5 OO
Somogyi-Zalud et al. (2002)	Four teaching hospitals: USA; deaths 80+	72^{LH}	86†	54	43	18	81	18	---	---
Twomey et al. (2007)	University hospital: UK; Acute elder unit deaths	25^{LH}	82.4	---	---	---	84	---	24	52
Verhofstede et al. (2017)	23 Acute geriatric hospital units; Belgium	$338^{2d\ BD}$	85.7 ± 6.52	---	---	6.0	---	---	69.1	71.6
Wilson (1997)**	Four hospitals: Alberta, Canada; Deaths 18+	56 YO $^{3d\ BD}$ 39 OO $^{3d\ BD}$	---	25 YO 7.7 OO	---	62.5 YO 59.0 OO	---	---	---	---

BD = Before death; †† = At time of death; LH = Treatment given during Last Hospitalization; d = days; h = hours; FT = Feeding Tube/NG; D = Dementia; ND = Non-dementia; C = Metastatic Cancer; HF = Heart Failure; YO = Young-old (aged 65 – 84); OO = Old-old (aged 85+); †=median; ‡ = BiPAP, CPAP, Ventilator; *Statistically significant; **Results calculated from study data provided.

Table 3

Hospital Use and Symptoms Experienced by Patients of Various Ages

Citation	Hospital Type: Place; Focus	Sample N $^{\text{Timeframe}}$	Age of Death (Mean ± SD)	Selected Interventions Prior to Death %					Symptoms %	
				ICU/SCU	Ventilator	FT/NG	DNR^{BD}	CPR	Pain	Dyspnea
Becker et al. (2007)	Large teaching hospital: Germany; deaths all ages.	226^{LH}	68.3	74^{LH} ($52^{\dagger\dagger}$)	53.1	---	64.6	---	---	---
Dendaas et al. (2001)	Large Mid-western academic medical center: USA; deaths all ages.	$100^{\dagger\dagger}$	---	47	---	---	86	---	---	---
Fins et al. (1999)	Large teaching hospital: New York; adult deaths.	200^{LH}	68	55.3^{LH} ($41^{\dagger\dagger}$)	45.7^{LH} ($37^{\dagger\dagger}$)	---	77	25	---	---
Goodlin et al. (1998)	Two major teaching hospitals: USA; consecutive deaths.	$104^{48h\ BD}$	68.9±12.9	38.5	30.0	34.6	89.0	11.5	47	51
Heyland et al. (2000b)	Canadian hospitals participating in CIHI; ICU/SCU deaths; all ages.	$70{,}116^{\dagger\dagger}$	---	15.27 NT 26.76 T	---	---	---	---	---	---
Middlewood, Gardner, and Gardner (2001)	Teaching hospital; Australia; cancer deaths all ages.	100^{LH} Cancer	66†	14^{LH} $7^{\dagger\dagger}$	12	13^{LH} $5^{\dagger\dagger}$	88	---	---	---
Moyano, Zambrano, and Mayungo (2010)	200-bed University hospital: Colombia; deaths all ages.	$182^{\dagger\dagger}$	---	49	---	---	---	---	---	---
Nadimi and Currow (2011)	176-bed acute care facility: Australia; deaths 18 +.	73^{LH}	61.4	48	---	---	88	---	---	---
Ohta and Kronefeld (2011)	Inpatient deaths, Maricopa County, Arizona; 65+.	3409^{LH}	79	80.1	42.4	---	---	---	---	---
Paice, Muir, and Shott (2004)	Large Midwestern Medical centre: USA; selected unit deaths.	$195^{48h\ BD}$	66.9± 16.4	---	30.3	33.8	91	---	77	78
Phua et al. (2011)	Large university teaching hospital: Singapore; non-ICU adult deaths.	$683^{24h\ BD}$	73.4± 14.1	Excluded	14	24.7	66.2	9.4	---	---
SUPPORT Investigators (1995)	Five teaching hospitals in USA; deaths 18+.	1150^{LH}	65†	38	46	---	79	---	50	---
Thurston et al. (2011)	Two full service Canadian hospitals; deaths all ages.	1018^{LH}	72.5	20.7 Y 15.0 O	---	---	87.5	18.4Y 12.1O	82.7 Y 75.0 O	---
Toscani et al. (2005)	40 Hospitals: Italy; General ward; deaths 18 +.	$370^{24h\ BD}$	77.1	---	---	3	---	---	75	70
Wilson (1997)	Four hospitals: Alberta, Canada; deaths 18+.	$137^{3d\ BD}$	70.9	27.0	---	24.1	86.9	2.9	---	---
Wilson and Truman (2002)	Alberta acute care hospital deaths, Canada; all ages.	7,429	70.5	$15.6^{\dagger\dagger}$	---	---	---	---	---	---

BD = Before death; †† = At time of death; LH = Treatment given during last hospitalization; d = days, h = hours FT/NG = Feeding tube/Nasogastric tube; SCU = Special care unit; Y = Young (aged 0 – 64); O = Old (aged 65+); NT = Non-teaching hospital; T = Teaching hospital; † = median; * = Statistically significant

Table 4

Qualitative Research Regarding End-of-Life Hospital care as perceived by Patients and/or Families; Mean/median age 75+

Citation/Method	Aim/Country	Participants	Results
Donnelly and Battley (2010) Qualitative analysis, interviews	To explore how families experienced the moment of death in hospital. IRELAND	Relatives of 15 deceased patients (n = 24). Mean decedent age 75.1; Range = 47 – 91.	Themes and issues: Hospital as place to die; cleanliness, preference, visiting hours, parking. Location within hospital: lighting, noise, lack of space, ward design, proximity of amenities for relatives, early awakenings at 0500. Quality of communication: the need to be kept informed, regular communication, continuity of care. Attributes of staff: skill, humanity, trust staff who are familiar, sensitive dignified care-family role as advocates, protectors.
Hawker, et al. (2006) Qualitative analysis, interviews	To evaluate nature and quality of EOL care in community hospitals ENGLAND	Bereaved carers of decedents aged 65+; (n = 51). Mean decedent age 80.2.	Themes: Locality of hospital; enabled carers to visit more frequently, Free parking an asset. Environment; clean, comfortable, friendly. Familiarity of hospital, nurses, and physicians. Nursing staff; sensitivity noted especially around time of death, Smaller hospitals viewed more positively than larger hospital. Issues of Concern: Unpredictable death, lack of qualified staff, noise.
Jacobs et al. (2002) Focus groups, chart reviews, interviews	To conduct an institutional assessment of EOL care practices in order to improve care. UNITED STATES	Physicians, nurses, bereaved family members. 30 patients from ICU; 30 patients from geriatric service (aged 75+) Patient mean age = 80. (Family; n = 31).	Family interview results: Greater satisfaction reported with physical care aspects (83%) than with emotional comfort (53%) received by patient. Pain relief (73%) preferred over extending life (20%). Excessive efforts and testing done to keep patient alive (27%). Many family members (50%) not aware death imminent until the final week. Inadequate communication, information, knowledge re: patient's condition limited family ability to actively participate in treatment decisions.
James, Andershed, and Ternestedt (2009) Hermeneutic approach, interviews	To gain an understanding of family member experiences of encounters with professional and non-professional care at the end of life. SWEDEN	Bereaved family members (n = 27). Decedent age range: 40 – 92.	Carer experience themes: Struggling to obtain treatment for their dying relative. Being left behind. Becoming partners with health care providers for sake of relative. Keeping illness at a distance for their relative. Waiting for death at their relative's side. Acting as experts and protectors.

Continued

Table 4 *(Continued)*

Qualitative Research Regarding End-of-Life Hospital care as perceived by Patients and/or Families; Mean/median age 75+

Citation/Method	Aim	Participants	Results
Payne et al. (2007) Principles of grounded theory, interviews	To examine patients and families' experiences of EOL care in community hospitals ENGLAND	Elderly patients 65+ admitted for EOL care in 6 hospitals (n = 18; Mean age est. 75). Family carers (n = 11).	Patients: Reported community hospitals cleaner, more comfortable, flexible in response to needs, not as distant as larger hospitals; nurses were kind and caring, but staff qualifications varied as compared to larger hospitals. Preference for private rooms varied. Families: Enjoyed accessibility; environment favorable. Enjoyed reclining chairs, unrestricted visiting. Many preferred private rooms, but such rooms in high demand.
Stajduhar et al. (2011) Thematic coding, interviews	To identify important areas of bereaved carer satisfaction with hospital care; develop a conceptual framework to understand features related to elements of care, their interpretation, and outcomes. CANADA	Bereaved family members (n = 24). Mean decedent age = 78.4. Continuing care, ICU, medicine, palliative care units of 4 settings.	Conceptual framework for quality EOL care consisted of tangible, interpretive, & personal/affective features. *Tangible features:* (a) What is or is not done; personal care, diagnosis, appropriate treatment/medication management, symptom control, psychosocial, emotional support, respecting values (b) What is said or not said; communication, keeping families informed about condition, what to expect. (c) "How it is done and how it is said" (p.264); provider behaviors, mannerisms, interpersonal interactions, caring, gentle, in-tune. (d) Care environment; calm, clean, free from excessive noise, comforts such as chairs/space, lighting, pleasant room, food quality. *Interpretive features* related to: (a) Health care system; procedure wait times, staffing, financial resources; staffing turnover, busy-ness of staff. (b) Individual provider characteristics; staff competence, communicating with compassion/caring, the way staff spoke to families and delivered care informed interpretations. *Personal and Affective features:* Outcomes expressed in feelings, relationships, roles. Good care instilled confidence, trust, appreciation, felt cared about. Bad environments generated anxiety, anger, regret, distress. Positive environments promoted calmness, emotional comfort. Environments, such as hallway care, generated distress.

Table 5

Quantitative Research Regarding End-of-Life Hospital care as Perceived by Patients (75+) and/or Families

Citation/Method	Aim/Country	Participants	Results
Addington-Hall et al., (1995) Interviews using adapted schedule of questions.	To investigate the quality of care received by stroke patients in the last year of life. ENGLAND	Bereaved family members (n = 237; 48% adult children or son/daughter-in-laws) 78% decedents aged 75+ (Age range: Under 55 – 85+) Hospital unit not identified.	Common symptoms in the last month of life included pain, mental confusion, low mood, urinary and fecal incontinence. Hospital in-patient care: Nursing care rated excellent (46%). Doctors rated excellent (29%). Room peaceful and quiet (43%). Privacy at all times (57%); no privacy (27%). Respondents treated very kindly when visiting (63%). Respondent knew deceased likely to die (58%); did not know (20%). Doctors informed respondents of likelihood of death (33%). Respondents were glad they did not know prognosis (64%).
Addington-Hall and O'Callaghan (2009) VOICES questionnaire	To compare the quality of the last three months of cancer care between hospitals and in-patient hospices. ENGLAND	Bereaved relatives (n = 40; 52.5 % adult children). 27.5% decedents aged 80+ (Range: 40 – 80+).	Families reported significantly better provision of information, nursing care, and treatment of pain in hospices as compared to hospitals. Nursing care rated excellent 83.3% of the time in hospices vs 38.9% in hospitals. Significant less satisfaction in hospitals regarding practical care, treatment of patient with respect and dignity by staff, and care from doctors.
Beccaro et al., (2009) VOICES follow-back study	To evaluate the prevalence of main symptoms, treatment, and outcomes of EOL care as provided to cancer patients who died in Italian hospitals. ITALY	Bereaved families (n = 364; 46.1% adult children). 61.0 % decedents aged 75+ (Age range 18 – 85+) No identification of location within hospital	Distressing symptoms were pain, nausea and vomiting, and dyspnea. Sufficient information given to make treatment decisions perceived by 29.9% of patients and 74.0% of caregivers. Information was provided sensitively (82.0%). Most caregivers rated overall hospital care good or excellent. Probability of satisfaction increased when physicians provided information about treatment to patients and families, when families were informed adequately about patient's condition, and when family informed about impending death ($p < 0.02$).
Bravell , Malmber, and Berg (2010) Telephone interviews 1 month after death rating care	To describe the last year of life for the oldest old while examining care trajectories, health and social networks, and activities of daily living. SWEDEN	Bereaved family members (n = 102; 80.5% adult children). Randomly selected oldest old decedents aged 86, 90, & 94 from Swedish population registry, mean age = 92.5.	21 oldest old died at hospital; only 5 in community. Proxies rated hospital care good (85.7%). Staff competence rated as very good (47.6%) or good (28.6%). Staff attitudes and treatment rated very good (52.4%) or good (28.6%).

Continued

Table 5 *(Continued)*

Quantitative Research Regarding End-of-Life Hospital care as Perceived by Patients (75+) and/or Families

Citation/Method	Aim/Country	Participants	Results
Brazil et al. (2013) Cross-sectional survey using aspects of FAMCARE & CANHELP tool	To assess family caregiver satisfaction with effectiveness of communication, and determine associated patient factors. CANADA	Bereaved family members (n=250; 33% adult children, sons/daughter-in-laws). (Mean decedent age 75.7) Various units including intensive care.	Overall good satisfaction with information sharing and communication (3.9/5 on 5-point Likert scale). Lowest scored items: providing information about adverse effects of treatment and how to manage symptoms; timing of end of life discussions, and family conferences to discuss illness (3.8/5). Highest scored items: how providers worked together as a team, and how closely team followed wishes of patient (4.2/5). Lower scores associated with longer stays and male gender. Higher scores associated with care in intensive care units.
Detering et al. (2010) Randomized Control Trial	To investigate the effect of advance care planning on the quality of EOL care for older patients. AUSTRALIA	Patients aged ≥ 80 Intervention group; n = 154; (mean age 85). Control group; n = 155; (mean age 84).	Patients randomized to receive advance care planning information while in hospital. Intervention group reported less anxiety, stress, and depression than control group; and higher satisfaction in overall hospital satisfaction, information sharing, being listened to, involvement in decisions, and family involvement in decisions. EOL wishes known and respected in 86% of intervention group (29 deaths) who died vs. 30% of control group (27 deaths).

Frank et al. (2012)
CANHELP questionnaire
	To assess impact of nurse facilitator-led quality improvement project while using CANHELP tool to improve EOL care on inpatient medical unit.
	CANADA
		1st cohort
		n = 33 patients;
		(Mean age 76.1).
		2nd cohort
		n = 34 patients;
		(Mean age 74.1).
		(55+ with serious illness, or 80+ with acute illness).
			Intervention:
			1st cohort: nurse facilitator interviewed patients and completed CANHELP. Greatest gap between level of satisfaction and importance identified.
			2nd cohort: nurse facilitator completed CANHELP and ESAS with patients; Gaps identified; nurse facilitator worked with teams to address gaps using identified strategies; follow-up questionnaire sent to patients 2 weeks post discharge.
			Statistically significant improvement seen in all 10 priority areas.

Formiga et al. (2007) Questionnaire; telephone interview	To evaluate circumstances related to death in non-cancer patients and caregiver opinion's regarding death; internal medicine department of 2 teaching hospitals. SPAIN	Bereaved caregivers of decedents aged 65 +; Decedents who had dementia, n = 37; (Mean age 87.2), Decedents who had heart failure, n = 65, (Mean age 81.4).	Caregivers were satisfied with information received (67.6%). Symptoms reported to be control in 55 % cases. Pain not controlled in 13.6%; uncontrolled dyspnea (45%). 66.5% said overall hospital care good or very good. Requests: single room, better information/communication, better treatment from nurses.

Continued

Table 5 *(Continued)*

Quantitative Research Regarding End-of-Life Hospital care as Perceived by Patients (75+) and/or Families

Citation/Method	Aim/Country	Participants	Results
Heyland et al. (2010a) CANHELP questionnaire	To identify high-priorities for care improvements for people with life-limiting illness and their families CANADA	Hospitalized patients with life-limiting disease Mean age 76.6 (n = 361). Family members (n = 193).	Areas requiring improvement common to both patients and family: Emotional support for patient, availability of doctor, need for doctors to listen to what patient/family had to say, receiving consistent information from doctors and nurses, receiving updates. Patient perspective: being at peace. Family perspective: discussions about location of care, use of life-sustaining technology, & receiving good care when family not present.
Heyland, Barwich et al. (2013) Interviews, chart audits, CANHELP questionnaire (domains related to communication and decision-making).	To inquire about advance care planning activities prior to hospitalization and measure concordance between patient/family preferences for care and documentation in chart. CANADA	Hospitalized patients 55 + with advanced illness & 80+ with acute illness. Participating patients - Mean age 80.0 (n = 278) Family members (n = 225; 53% adult children).	Few orders written on chart stating goals of care. Only 30.2% agreement between patient preferences for care and documentation on medical chart. 28.1% of patients and 34.6% families preferred comfort measures only, but this was only recorded in 4.5% of patients' charts and in 17% charts represented by family respectively. Lowest areas on CANHELP questionnaire for patients related to discussions regarding future location of care and what to expect regarding end stage illness. Lowest areas on CANHELP for families were future location of EOL care and use of life-prolonging technology.
Natan et al. (2010) Adapted questionnaire; 5-point Likert scale	To compare importance of inpatient needs among patients, families, physicians, and nurses. ISRAEL	73 Geriatric inpatients 58 family members (63% adult children) 249 nurses 71 physicians (Mean age of patient not provided).	Five needs most significant for all: to be free from pain, maintain dignity, have attentive staff, feel comfortable with the nurse, and prevent respiratory issues. Elderly patients not interested in life prolonging measures when there was no cure; 86.4% would want truth shared regarding their condition; 57% would want to die at home. Also important: Maintaining hygiene, receiving updates on medical condition, have opportunities to discuss fears and anxieties; being involved in care policies and decisions. Family members valued updates on condition, opportunities to discuss fears, cleanliness, involving patients in care/policy decisions.
Sadler et al. (2014) CANHELP questionnaire ICU/PCU/hospital ward	To identify patient and institution factors linked with quality EOL care among hospitalized patients, and determine priority target areas to enhance care. CANADA	Random sample of Bereaved family members (n = 92; 31.9% adult children) (Mean decedent age 75.7)	ICU most common place of death (45.7%). 45.7% of patients died not in location of preference. Those whose loved one had died in preferred location were 1.9 times more likely to be satisfied with quality of EOL care ($p < 0.001$).

Continued

Table 5 *(Continued)*

Quantitative Research Regarding End-of-Life Hospital care as Perceived by Patients (75+) and/or Families

Citation/Method	Aim/Country	Participant	Results
Young et al. (2009) VOICES questionnaire	To explore determinants of satisfaction with health services in the last 3 months and 3 days of life as described by bereaved families of patients who died from stroke in an institution. ENGLAND	Bereaved relatives (n = 183; 55% adult children) 66% decedents aged 80+.	Overall satisfaction with care received in last three days best predicted by: (a) help available for deceased person (personal care and nursing care); (b) family involved in treatment and care decisions as much as they wanted; and (c) carer believed decedent died in the right place. Overall satisfaction with overall care from doctors and nurses best predicted by: (a) the ability of informants to discuss worries and fears regarding condition, treatment, and/or tests of decedent, and (b) doctors and nurses were knowledgeable about decedent's condition.
You et al. (2014) CANHELP questionnaire (global satisfaction, and domains related to end-of-life communication and decision-making)	To determine which elements of goals of care discussions where most important to patients and families; and to determine concordance with hospital care. CANADA	Patients 55 + with advanced illness & patients 80+ with acute illness. Patients (n = 233), (Mean age 81.2) Family members (n = 205; 61% adult children).	Goals of care discussions: Patients & families rated same 5 key elements of EOL discussions as most important (being asked about preferences for care and values, discussing prognosis, providing opportunities to discuss fears and concerns, and asking if patient/family had additional questions). Concordance with care between patients/families and hospital chart documentation: patients 29.7%, families 35.6%. Discussion of greater number of elements was associated with higher CANHELP satisfaction scores.

Abbreviations: End-of-Life (EOL); Canadian Health Evaluation Project (CANHELP) questionnaire; View of Informal Carers-Evaluation of Services (VOICES) questionnaire; Intensive care unit (ICU); Palliative care unit (PCU); Edmonton symptom assessment scale (ESAS).

CHAPTER THREE

RESEARCH METHODOLOGY

This chapter outlines the research methodology used for this mixed methods study; beginning with the research questions, the research design, and the data collection and analysis procedures associated with the quantitative and qualitative components of this research study. Ethical considerations, such as informed consent and confidentiality, and measures to ensure research quality are also reviewed.

Research Questions

As indicated, the aim of this study was to develop a substantive theory of high-quality EOL hospital care for dying non-surgical hospital patients aged 85 and older, after establishing population-level socio-demographic and hospital utilization information for this age group. As such, this study was designed to answer the research question: What do adult children of parents aged 85 and older consider as high-quality hospital care for their parent when their parent's non-surgical admission to hospital ends in death? Moreover, to develop a greater understanding of the socio-demographic and health-related characteristics of advanced-age decedents in Ontario, the following questions were addressed:

- *Research Question 1:* What are the socio-demographic and health-related characteristics of advanced-age adults (85+) who died in an acute care hospital in Ontario during the fiscal year of April 1st, 2014 through March 31st, 2015?
- *Research Question 2:* What was the percentage of hospital decedents aged 85+ designated as having a palliative diagnosis (ICD 10 code, Z515)?

- *Research Question 3:* What was the pattern of hospital use in relation to variables such as length of stay [LOS] and the percentage of alternative level of care [ALC] days among older decedents aged 85+?
- *Research Question 4:* What types of life-sustaining treatment did older adults aged 85+ receive during the last hospital stay that ended in death? (i.e. chemotherapy, blood transfusions, dialysis, cardiopulmonary resuscitation, mechanical ventilation, admission to special care units [SCU], and deaths in a SCU.)

Research Design

A mixed methods quantitative – QUALITATIVE priority-sequence research design was used for this study (Morgan, 1998). Mixed methods is a research design whereby researchers collect, analyze, and integrate both quantitative and qualitative data while assigning sequence and priority to one or to both types of data within a single study or a series of studies (Creswell & Plano Clark, 2011). The primary purpose of using both quantitative and qualitative approaches is to gain a greater understanding of the research subject than either approach could do alone (Creswell & Plano Clark, 2011; Leech & Onwuegbuzie, 2009). This pragmatic view of mixed methods research embraces the philosophy that there are multiple ways of understanding and making sense of the world (Creswell & Plano Clark, 2011), and that different paradigms can co-exist and so can be complementary (Johnson, Onwuegbuzie, & Turner, 2007). Moreover, using both quantitative and qualitative approaches in the same study capitalizes on each of their strengths and offsets weaknesses (Onwuegbuzie & Leech, 2005), thereby enhancing the depth and breadth of knowledge gained while enhancing descriptions and understanding of issues (Johnson et al., 2007).

Mixed methods research has become increasingly popular in disciplines such as nursing, education, and program evaluation (Leech & Onwuegbuzie, 2009). Leech and Onwuegbuzie (2009) indicated that an increasing number of mixed methods research studies have been published, with many journals now routinely publishing mixed methods research reports (for example, *Research in Nursing and Health).*

In this mixed methods priority-sequence design, the researcher first collected and analyzed quantitative data, a phase that was based on the traditional positivist paradigm (Morgan, 1998). This data analysis served four purposes: (a) to describe older people (aged 85+) who died in hospital, (b) to describe the health care provided in hospital to older persons aged 85+ who died in hospital, (c) to serve as a context to better understand and integrate findings with the qualitative phase, and (d) to inform data collection for the qualitative phase by highlighting topics requiring further exploration.

In the second phase of this study, a grounded theory approach was used to guide the qualitative interviews and qualitative data analysis. The objective of this phase of the research was to explore adult children's perceptions of the quality of the hospital care received by their parent aged 85+ during the last non-surgical hospital stay that ended in death. Topics identified in the quantitative phase were integrated into interview questions and probes. Results of the quantitative and qualitative phases were then integrated in the discussion section.

Quantitative Phase

Quantitative data analysis. After obtaining ethics approval from the University of Alberta Human Research Ethics Board (Pro00060204) for all aspects of this mixed methods study, the Canadian Institute for Health Information (CIHI) provided discharge abstract data (DAD) containing information on Ontario acute care hospital decedents. CIHI compiles the

DAD from the administrative, clinical, demographic information regarding hospital discharges that is received from Canadian acute care hospitals, regional authorities, and health departments (CIHI, 2014b). All provinces and territories except Quebec submit this data to CIHI (CIHI, 2014b). CIHI has a data quality framework in place to ensure the accuracy of the data (CIHI, 2014b).

Descriptive and comparative statistics were generated using SPSS ® version 23 software (IBM Corp, 2015). Frequencies were run on all variables to ensure completeness of the CIHI DAD and ensure missing data were minimal or entirely absent. Descriptive analysis was then used to answer the first research question: “What are the socio-demographic and health-related characteristics of advanced-age adults (85+) who died in an acute care hospital in Ontario during the fiscal year of April 1st, 2014 through March 31st, 2015?” The socio-demographic variables analyzed were age, gender, place of residence (rural/urban), and type of residence (home, long term care, or other). Urban residence was defined as people living within Census Metropolitan Areas (CMAs) and Census Agglomerations (CAs), locations known to have 100,000 or more residents (CIHI, 2006). People living outside of CMAs and CAs are considered rural according to CIHI (2006). Chi-square analysis was used to compare differences among nominal variables, and the Kruskal Wallis test was used for continuous variables that did not have a normal distribution curve (e.g. age) (Field, 2009). Bonferoni analysis was used to determine significant differences between groups.

Descriptive analysis was also used to explore the most responsible diagnosis (MRDx) for the last hospital admission for all decedents aged 85+. In the DAD, all diagnoses are coded according to international coding standards developed by the World Health Organization (CIHI, 2014d). This system is entitled the *International Statistical Classification of Diseases and*

Related Health Problems, 10th Revision (ICD-10); with a Canadian enhancement known as the ICD-10-CA (CIHI, 2014d). To prepare the MRDx for data analysis, the corresponding ICD-10-CA codes were transformed into disease chapters using the first digit of the code, and then into diseases using the first three digits of the code.

Descriptive analysis was also used to answer the second research question: "What was the percentage of hospital decedents aged 85+ designated as having a palliative diagnosis (ICD 10 code, Z515)?" First, dummy variables were created for palliative care diagnoses. A palliative care diagnosis was identified using the ICD-10-CA-code Z515. The diagnosis, palliative care, is listed as the MRDx when a patient is admitted to hospital for the main purpose of receiving palliative care or when the patient received palliative care for the majority of the hospital stay (CIHI, 2015). A diagnosis of palliative care is listed in subsequent diagnostic variables as a Type 1 (pre-admit co-morbidity), or a Type W, X, or Y (service transfer) diagnosis when someone is admitted to hospital for treatment of reversible conditions or when the patient's care plan transitions to a palliative focus (CIHI, 2015). Dummy variables were also created to identify patients who were admitted to hospital with a previously known palliative care plan as indicated by the diagnostic code prefix 8 (CIHI, 2015).

Next, after extracting and grouping advanced-aged decedents who died in SCUs, the 85+ group was divided into four main groups using the CIHI DAD main patient service code. The main patient service code describes groups of similar patients who have related diseases and treatments (CIHI, 2014 – 2015). The four groups included medicine, surgery, palliative care, and SCU. For example, decedents who received care mainly from main patient services such as neurology, cardiology, and general medicine were grouped under medicine. Decedents who received surgical services, such as general surgery, orthopedic surgery, or thoracic surgery, were grouped under surgery. Similarly, decedents who received services related to the main patient service of palliative care were grouped under palliative care, and individuals who died in a SCU were grouped under SCU. A total of 52 advanced-age decedents were not included in the latter analysis as they represented hospital admissions occurring for other reasons than medical or surgical (i.e. ALC only, a rehabilitation unit, or psychiatry).

To answer the third research question, "What was the pattern of hospital use in relation to variables such as length of stay [LOS] and the percentage of alternative level of care [ALC] days among older decedents aged 85+?," this study explored the following hospital use variables using descriptive and comparative statistical procedures: (a) type of admission (direct or through the emergency room); (b) type of hospital (small, medium, or large community hospital, or teaching hospital); (c) admission to special care units, such as an intensive care unit or cardiac care unit (Canadian Institute of Health Information 2014e); (d) death in a SCU; (e) total length of stay (LOS) days; and (f) number and percent of alternative level of care (ALC) days during the terminal admission. The total length of stay (LOS) was defined as the difference in days between the date of a patient's hospital admission and the discharge through death or otherwise (CIHI, 2014-2015). Average LOS is a common measure of hospital efficiency, with more days usually resulting in increased hospital costs (OECD Data, 2016). In contrast, Alternative Level of Care or ALC is a term used by hospitals "to describe patients who occupy a bed but do not require the intensity of services provided in that care setting" (CIHI, n.d., para 1). A common thought is that patients designated as ALC are using limited and expensive resources while awaiting discharge to a more appropriate care location (CIHI, 2009).

The type of hospital was defined according to CIHI's (2016) peer group methodology. A teaching hospital is one that has been designated a teaching hospital by the province. Community hospitals are grouped according to the volume and complexity of patients using hospital services; for example, a small hospital services less than 2,000 weighted cases, medium hospitals serve more than 2,000 weighted cases, and large community hospitals serve 10,000 or more weighted cases (CIHI, 2016).

Descriptive and comparative analyses were also used to answer the fourth research question: "What types of life-sustaining treatment did older adults aged 85+ receive during the last hospital stay that ended in death?" The CIHI DAD utilizes a standardized coding system entitled the *Canadian Classification of Health Interventions* (CCI) to code interventions (CIHI, 2015). CCI codes were used to examine interventions such as: (a) CPR, (b) mechanical ventilation, (c) chemotherapy, and (d) kidney dialysis. Blood transfusions were examined using the CIHI DAD blood transfusion flag. There are approximately 20 available variables to code interventions within the CIHI DAD. To prepare the CIHI DAD intervention codes for analysis, dummy variables were created for each selected intervention. Each individual dummy variable was then summed to determine whether an intervention was provided at any time during the final hospital stay. To determine the unique characteristics of advanced-age decedents in the medicine (non-surgical) group, the researcher conducted a binary logistic regression analysis.

Qualitative Phase

The qualitative research phase used a constructivist grounded theory approach as outlined by Charmaz (2006, 2014), to obtain adult children perceptions of the quality of EOL hospital care provided to their parent aged 85+ who died in hospital. Grounded theory is a methodology that aims to construct theory about important issues in people's lives through the interpretation of participant stories (Mills, Bonner, & Francis, 2006b). Through an interactive process with participants, the researcher co-produces the discovered meanings and realities associated with a phenomenon (Mills et al., 2006b). Hence grounded theory is based on symbolic interactionism; a theory that emphasizes the dynamic process of the person interacting with the environment (Oktay, 2012). The "self" continually grows and changes as the person shares significant symbols and meanings through the process of interacting with others (Oktay, 2012). In contrast to positivist views of reality embedded in traditional grounded theory approaches, constructivist grounded theory holds a relativist ontology and subjectivist epistemology (Mills, Bonner, & Francis, 2006a). A constructivist approach emphasizes reciprocity between researcher and participant, the co-creation of meaning, and a theory based on both party's experiences (Mills et al., 2006a). In addition, there is an attempt to eliminate any power imbalances between the researcher and participant (Mills et al., 2006a).

Grounded theory is characterized by four key components: (a) theoretical sensitivity, (b) constant comparison, (c) theoretical sampling, and (d) theoretical saturation (Oktay, 2012). Theoretical sensitivity refers to the researcher's analytical ability to envision and transform raw data into theoretical concepts (Oktay, 2012). This ability is enhanced by the researcher's familiarity of existing theories, as well as the researcher's personal and professional experience (Oktay, 2012). As data is gathered, the researcher constantly compares each case for similarities and differences, and refines conceptual categories throughout the process (Oktay, 2012). Theoretical sampling is carried out by choosing participants purposefully to further delineate the evolving theory (Creswell, 2013). Interviews continue until the data reaches a point of theoretical saturation; that is, no additional data contributes to new concepts or categories and the theory is well supported (Oktay, 2012).

Participants. This study used purposeful sampling to recruit adult children who had experienced the death of a parent aged 85 or over in an acute care hospital in Southwestern Ontario. The recruitment strategies were as follows:

- Acute care hospitals in Southwestern Ontario were approached to send letters to recently bereaved individuals (see Appendix B-Sample recruitment letter).
- Ads were placed in newspapers.
- Flyers were posted in grocery stores, restaurants, physician's offices, and hospitals (see Appendix C-Sample poster).
- Flyers were emailed to intermediary individuals and groups; such as the London Regional Advance Practice Nursing Group, patient experience professionals at local hospitals, physicians, and interdisciplinary staff members who work in a hospital setting.

The researcher screened volunteers according to the following inclusion and exclusion criteria, and provided them with information about the research study. The adult child was included if he/she: (a) had experienced a death of a close/beloved parent, step-parent, or parent-in-law aged 85 or over preferably within the past two years; (b) had visited the parent at least once in the hospital and provided support to the parent in regards to care decisions during the parent's hospital stay; (c) was 18 years of age or older; (d) understood and spoke English; (e) was able to provide information regarding the EOL care provided in hospital to their advanced-age parent; and (f) was able to participate in one or two interviews. In addition, their parent died during a non-surgical admission in an acute care hospital in Ontario. The two-year time frame was chosen to balance issues related to sensitivity toward bereaved individuals and issues associated with recall (Williams, Woodby, Bailey, & Burgio, 2008). Williams et al. (2008) suggest greater recall is associated with highly emotive events, such as the death of a loved one.

The exclusion criteria were: (a) the parent's death occurred while in the emergency room, or in a specialty unit such as the ICU; (b) the death followed surgery undertaken in the same hospitalization; (c) the death occurred as a result of trauma (other than a fall), accident, or suicide; and (c) the parent had been cared for by the researcher previously in her clinical role as a nurse practitioner on a geriatric consult team.

Informed consent. After screening interested volunteers for inclusion and exclusion criteria, all participants provided informed consent after the researcher explained the purpose of the study, the process involved, and the potential risks and benefits of the study. The researcher provided a letter of information about the study in person or by email (see Appendix D – Letter of information). Participants were informed that: (a) confidentiality would be maintained and their name would not be used in any research report, (b) participation was voluntary, (c) they could request to withdraw from the study at any time during the data collection phase, and (d) they could choose not to answer a particular question if they were not comfortable doing so. Participants then signed a consent form if they agreed to be in the study (Appendix E – Consent form). Verbal (phone) consent was obtained in one case due to accessibility issues. In this case, the researcher read the letter of information and consent form and documented the participant's verbal consent. Consent was confirmed at the beginning of the recorded interview.

Before the interview, participants completed a questionnaire designed to obtain demographic information and health related information about their parent (Appendix F – Demographic information). The questionnaire also asked participants to rate the quality of EOL hospital care received by their parent on a visual analogue scale (0 = extremely poor – worst ever; 10 = outstanding – couldn't be better). After reviewing the questionnaire, a semi-structured interview was conducted (see Appendix G for Interview protocol).

Interviews. The interviews took place either in the participant's home (n = 9), a private office (n = 1), over the phone (n = 4), or a restaurant (n = 1). Six participants were interviewed in dyads. In these cases, questions were directed to each participant to ensure equal participation. Two participants were interviewed twice to validate the components of the developing theory. Interview questions and probes were derived from examples provided by Charmaz (2014), other grounded theory studies (e.g. Duggleby et al., 2010), and sensitizing concepts originating from the researcher's professional palliative care nursing experiences and patterns identified in the quantitative study phase as well as the literature review. According to Charmaz (2014), a sensitizing concept is a broad idea that sparks thinking and inquiry about a topic, but does not command the inquiry. In this study, the sensitizing concepts of predictability of decline and the adult child's awareness of impending death were explored by asking adult children about their parent's illness and decline and when children became aware that their parent was dying. The main interview questions, however, focused on: (a) the most significant events related to the hospital care provided to advanced-age parents as perceived by adult children, (b) how adult children perceived the provision of EOL care, (c) what helped or hindered the provision of EOL care to their advanced-age parent and to themselves, and (d) how the quality of care impacted their parent and themselves (i.e. emotions, memories, and other outcomes, etc.). The interview guide served as a flexible tool to guide the three phases of questioning in each interview; initial open-ended questions, intermediate questions, and ending questions (Charmaz, 2014).

Initial questions aimed at preparing the informant about the topic area, and these established a sense of comfort and rapport (Charmaz, 2014). The researcher first began to develop an understanding of the informant and the background of his/her parent's illness (Charmaz, 2014). Examples of questions included, "Please tell me about you, your occupation, and your family," "Tell me about your parent's illness and how he/she came to being in hospital," "What was your role as his/her son or daughter?" and "Describe what that was like for you."

Intermediate questions were designed to delve deeper into areas of the informant's experience (Charmaz, 2014). Informants were asked questions such as "Please describe your experience in relation to the hospital care received by your parent." Informants were prompted to describe their experience in detail including what happened, when, and what informant thoughts and feelings were in response to arising situations (Charmaz, 2014). Informants were also prompted as to when they first became aware that their parent was dying. The interviewer remained alert to common situations or issues that occurred and how they unfolded as well as the antecedents, influences, and consequences to those experiences (Creswell, 2013). Both positive and negative case examples were explored to gain breadth to different ways of experiencing hospital care.

The interview concluded with summary questions, such as "Now that you've had this experience, how would you define high-quality EOL care?" Informants were also asked if there was anything else they would like to add (Charmaz, 2014; Patton, 2002). During the interview, the researcher used essential interviewing skills, notably active listening, open-ended questioning (Charmaz, 2014; Patton, 2002), and clarifying meanings (Kvale, 1996). Over time, the questions were modified as interviews proceeded and a beginning theory began to take shape (Charmaz, 2014). At the end of the interview, all participants were given resources to call upon if needed. Resources included the Canadian Mental Health Association crisis line number, a booklet entitled "Seasons of the Heart" (contains bereavement counselling resources that are available in the London, Ontario and surrounding area), and a pamphlet regarding grief.

Avoiding harm. Conducting research with bereaved individuals requires that all researchers protect the rights and wellbeing of all participants, while avoiding harm as much as possible (Stroebe, Stroebe, & Schut, 2003). Grieving individuals are potentially vulnerable when recounting highly emotive experiences such as the death of a loved one (McCosker, Barnard, & Gerber, 2001; Parkes, 1995). Reactive emotional distress is not unique when participating in research related to trauma or bereavement (Hynson, Aroni, Bauld, & Sawyer, 2006; Newman, Risch, & Kassam-Adams, 2006). Newman et al. (2006) asserted that while emotional distress may occur, evidence suggests that there is a low risk of emotional harm from participating in such research. In fact, many benefits have been reported by trauma survivors (Newman et al., 2006), bereaved parents (Hynson et al., 2006), as well as next-of-kin reporting on after-death studies on the quality of EOL care (Rosenblatt, 1995; Williams et al., 2008). Benefits included having an opportunity to tell their story and help others through participating in research (Hynson et al., 2006; Newman et al., 2006; Rosenblatt, 1995). Other reported therapeutic benefits include catharsis, validation, empowerment, and giving a voice to those who feel disenfranchised (Benzein, Norberg, & Saveman, 2001; Corbin & Morse, 2003; Hynson et al., 2006).

Strategies to minimize harm in this study included using a flexible interview approach and monitoring for participant distress as evidenced by verbal or non-verbal gestures, such as fidgeting, hesitation, or crying (Williams et al., 2008). Respondents were given time to express their needs and concerns (Parkes, 1995). The researcher also provided respectful attentiveness to each participant's responses by offering empathetic listening, silence, and support as appropriate.

Data analysis. Data analysis in this grounded theory study phase began immediately after the researcher transcribed the first interview (Sbaraini, Carter, Evans, & Blinkhorn, 2011). Both initial and focused coding was conducted (Charmaz, 2014). Initial coding involved careful line-by-line and incident-by-incident reviewing of the data in the first two transcripts, followed by incident-by-incident reviewing of data for the remainder of the interviews (Charmaz, 2014). During this time, the researcher remained open to varying possibilities of theoretical direction (Charmaz, 2014). Initial "in-vivo" codes were created based upon the words or ideas expressed by informants; these often described strong emotion, actions, or concepts related to symbolic interaction (Oktay, 2012). The researcher remained alert for significant processes and the meanings, feelings, thoughts, and consequences related to those processes (Charmaz, 2014; Duggleby et al., 2010). Coding in gerunds (words ending in 'ing') aided in analyzing processes and identifying connections implicit in the data (Charmaz, 2014).

Focused coding was used to organize the most significant and most frequent initial codes that best accounted for the data (Charmaz, 2014). Theoretically rich codes, patterns, and gaps were identified, and the most valuable focused codes then became the core of further analysis (Charmaz, 2014). Recurring participant statements were treated as theoretically plausible and were used to help develop tentative categories (Charmaz, 2014). The researcher used constant comparative analysis to compare incidents with incidents, codes with codes, codes with categories, and categories with categories ensuring best conceptual fit (Birks & Mills, 2011; Charmaz, 2014; Oktay, 2012). The researcher then used theoretical sampling, a process whereby the researcher selects individuals to elicit specific information to further clarify properties of categories, distinguish between categories, and solidify relationships between them (Charmaz, 2014). Data collection ended when data saturation was obtained; that is, when no new information was obtained and no new understandings of the collected data were evident.

Field notes and memos. Field notes and memo-writing were integral throughout the data analysis process. The researcher made notes during interviews and formalized these field notes immediately after the interview. Field notes formed a basic outline of the participant's experience, captured key words and phrases spoken during the interview, and included observations about the environment and the participant's reactions. The researcher documented reflective comments and questions to explore during subsequent interviews. All field notes were kept in an electronic file on the University of Alberta's Health Research Data Repository (HRDR) for safekeeping, with all data for this study to be kept secure for five years as per the University of Alberta's expectations.

Memos were maintained in an electronic journal. Memo-writing, according to grounded theory analysis, assist the researcher to: (a) reflect and capture thoughts regarding data gathered, (b) crystalize further questions and directions to pursue, (c) identify assumptions, (d) make connections between codes, and (e) develop categories upon which to begin framing the analysis (Charmaz, 2014). Memos also served as a decision-making audit trail recording how data was extracted, themes were labelled, and conclusions were derived (Birks, Chapman, & Francis, 2008). Moreover, memos served as a medium for reflexive writing about the researcher's impressions and reactions regarding the participant's experience as well as the assumptions revealed (Sbaraini et al., 2011). Through memo-writing, focused codes were raised to categories by identifying which are most significant to the process being studied (Charmaz, 2006). Analytical narratives defined and identified properties of each category; specified conditions, changes, and consequences related to each category; and demonstrated how each category is related to others (Charmaz, 2006; Oktay, 2012).

The final step in this grounded theory analysis involved the theoretical sorting, diagramming, and integrating of analytical memos (Charmaz, 2014). A model was then created representing the major categories and the relationships between them. Although focus groups were planned as a method to gain participant feedback, the majority of participants were not interested in attending. Instead, participant feedback was gathered during initial and subsequent interviews.

Qualitative data management. First, to ensure confidentiality, all tape-recorded interview files and field notes were uploaded on a secure server (the University of Alberta's HRDR) using secure file transfers. The researcher or CONSENSIA®, a transcription service contracted by the HRDR, transcribed the interview data verbatim (6 and 8 transcripts respectively). The researcher then reviewed transcripts for accuracy and removed all identifying information. The researcher next used the NVIVO® version 11 data management system (NVIVO, 2016) to sort data into codes and categories. Electronic data management systems such as NVIVO are able to manage large quantities of qualitative data (Malterud, 2012) and have been used successfully in grounded theory studies (Bringer, Johnston, & Brackenridge, 2006; Duggleby et al., 2010). After a minimum of five years after the research is completed, as indicated above, tape-recorded interviews and transcripts will be deleted from the server, and all other electronic and paper data will be destroyed.

Mixed Methods Integration

Mixed methods integration refers to the process where the researcher combines two forms of data together or uses one to build on the other (Creswell & Plano Clark, 2011). Mixed methods integration occurred at two points in this research study. First, pattern inferences regarding most responsible diagnoses and hospital use (e.g. use of the emergency room, length of stay, etc.) by advanced-age decedents were integrated into questions in the qualitative phase of the study. As mentioned earlier, the parent's course of illness (predictability of decline) and the adult child's awareness of the impending death were used as sensitizing concepts in the qualitative phase. Second, mixed methods integration occurred in the discussion chapter as a reflection upon patterns and inferences were drawn from the quantitative and qualitative results (Creswell & Plano Clark, 2011; Moran-Ellis et al., 2006). The researcher aimed to identify common themes between the quantitative and qualitative results; linking hospital use, decedent characteristics, and adult children's perceptions of the quality of EOL hospital care provided to their advanced-age parents. In this manner, a greater sense of the research problem as a whole was realized (Moran-Ellis et al., 2006).

Ensuring Validity and Research Quality

The concept of validity in mixed methods research has received increasing attention (Cresswell & Plano Clark, 2011). Based on differing epistemologies, quantitative and qualitative research methodologies approach validity differently (Dellinger & Leech, 2007; Lincoln & Guba, 1985; Onwuegbuzie & Johnson, 2006). In this sequential mixed methods research design, both quantitative and qualitative validation strategies that were appropriate for each individual method were employed to ensure quality. The purpose of the quantitative portion was to contextualize and complement the qualitative data (Morgan, 1998). In this study, the socio-demographic profile of advanced-age adults who died in an acute care hospital in Ontario and the type of hospital care received provided a context within which to better understand and integrate findings from both phases.

The quantitative phase of this research study used decedent information from the CIHI DAD. There is a high degree of internal and external validity with this database. The CIHI collects and maintains this database according to defined quality standards (CIHI, 2014b). Standardized ICD-10-CA and intervention codes (CCI) are utilized, and data are subjected to periodic external data accuracy checks (CIHI, 2014b). In 2004, for example, the CIHI conducted a data quality check of the DAD following the first year of the ICD-10-CA/CCI implementation which confirmed the strength of the database while revealing limitations in other areas (CIHI, 2005). CIHI coding experts conducted data re-abstraction from 20 sites in British Columbia, Ontario, and other selected areas throughout Canada (CIHI, 2005). There was a 96% to 100% coding agreement regarding non-medical data elements across the regions, a 93% to 95% match regarding diagnostic codes, and a 96% to 99% match regarding intervention codes (CIHI, 2005). Discrepancies were related to a variety of coding issues, such as transcription errors, different interpretation of documentation, missing chart information, and coding contrary to CIHI standards (CIHI, 2005).

CIHI has conducted similar coding agreement audits of data elements throughout the years (CIHI, 2014b). In the year 2006-2007, an interim guideline was released adding the palliative care diagnostic code, ICD-10-CA code Z515*,* to indicate a person with a terminal illness had received palliative care services during their hospitalization (CIHI, 2012). In 2009-2010, this code had a 96.4% agreement rate when the database was confirmed through chart review (CIHI, 2012). While coding is not an exact science and presents some limitations, the DAD database provides valuable information about hospital care provided throughout Canada, except Quebec. As a quality measure, education is offered to hospital personnel to ensure accurate coding (CIHI, 2014c).

Several frameworks exist to ensure quality and rigor in qualitative research (Charmaz, 2014; Creswell, 2013; Sandelowski, 1986). The qualitative component of this research study used the criteria of credibility, resonance, usefulness, and originality as outlined by Charmaz (2014); as well as reflexivity and auditability. Credibility is established by accurately presenting the multiple realities of a phenomenon in such a way that people having the experience would recognize it as their own (Sandelowski, 1986; Sikolia, Biros, Mason, & Weiser, 2013). Strategies to ensure credibility for this study were: (a) gathering, taping, and transcribing rich descriptions of participant's experiences (Creswell, 2013); (b) prolonged engagement in the field (Creswell, 2013); (c) making systematic comparisons between a wide range of observations and categories (Charmaz, 2014); (d) ensuring coding categories and examples used to present the data were representative of the data and had logical links (Charmaz, 2014; Sandelowski, 1986); and (e) conducting member checks during interviews as a method of soliciting feedback about the conclusions drawn from interviews (Maxwell, 2013; Merriam, 2002; Sandelowski, 1986). Resonance pertains to the sudden intuitive grasp, the striking experience, that is deeply understood by the reader (de Witt & Ploeg, 2006). Feedback was requested from three informants as to whether categories and descriptions captured the informants experiences and if there were any components that were missing (Creswell, 2013).

The substantive theory that was developed on high-quality EOL care for advanced-adults strives to be both useful and original. The substantive theory builds upon previous knowledge and offers new insights regarding the concept of high-quality EOL care (Charmaz, 2014). As Charmaz (2014) indicated, the substantive theory will demonstrate usefulness when it can guide everyday situations. In this case, the developed substantive theory can help clinicians to: (a) understand the experience of adult children who are facing the death of an advanced-age parent in hospital, (b) understand important aspects of high-quality EOL hospital care as perceived by adult children, and (c) implement interventions to improve the EOL care provided to the patient and family.

Two major threats to validity in qualitative research are researcher bias and the researcher's influence on the individual studied (Maxwell, 2013). The researcher used reflexivity and the process traditionally known as bracketing as a means of reflecting on her assumptions throughout the research process. Bracketing (or epoche) is a process where researchers suspend their past experiences as best as possible in order to view a phenomenon with a fresh perspective (Creswell, 2013). Past experiences and assumptions form a lens for interpreting the world, and this impacts what topics and processes the researcher sees as important (Charmaz, 2014). However, bracketing out one's own experience is a difficult state to achieve (Cresswell, 2013). Instead, constructivist grounded theorists acknowledge that the researcher is not a neutral observer and that the researcher's values and beliefs influence the construction of meaning in ways they may not always be aware (Charmaz, 2014). Therefore, to avoid undue influence of their presuppositions on the research process, constructivist grounded theorists engage in the process of reflexivity (Charmaz, 2014). Consequently, for this study, the researcher (an experienced gerontology and palliative care nurse) did not bracket but instead used reflexivity throughout the data gathering and analysis phase.

According to Merriam (2002), reflexivity refers to the critical self-reflecting process regarding the researcher's position in relation to the values and assumptions that underlie decisions occurring throughout the research process. More specifically, during this study, the researcher engaged in the process of self-reflection through the writing of memos in an electronic journal. This process acted as a means to ensure that researcher bias did not influence participant responses or the researcher's interpretation. In this study, the researcher used several self-reflective strategies. First, the researcher identified her own presuppositions that had the potential to influence interpretation of qualitative data. For example, the researcher identified that her previous palliative care experience and knowledge of palliative care principles may influence the interpretation of the categories associated with high-quality EOL care. To avoid preconceived notions from leading interpretation, the researcher was reflective and ensured categories were developed from participant voices in an iterative manner. Second, while sensitizing concepts (e.g. adult child's awareness of their parent's impending death) were used as a point of departure for qualitative inquiry, the researcher was cautious and reflective not to allow these concepts to dictate data analysis (Charmaz, 2014). Third, during interviews, the researcher was reflexive in monitoring her influence on participants' responses, while using open-ended questions, avoiding leading questions, and monitoring her own verbal and non-verbal responses to participant stories during interviews (Patton, 2002). Questions also avoided negative and potentially leading language (Patton, 2002). Reflections of interviews were written mainly in field notes directly after the interview and included tips for future interviews.

Two additional measures of ensuring quality in this research included auditability and peer review. Auditability contributed to the study's confirmability and in this study was addressed by maintaining a decision trail throughout the study (Sandelowski, 1986; Sikolia et al., 2013). Memos act as an audit trail outlining how data was collected, essential themes were identified, and decisions were made throughout the study (Merriam, 2002).

This study also incorporated a peer review process as a natural element of the dissertation process (Merriam, 2002). Student advisors and committee members examined and provided feedback regarding research activities, process, and findings to ensure the reliability of results

(Sikolia et al., 2013). Committee members also challenged the student about the methods, meanings, and the interpretations formulated during the dissertation defense (Creswell, 2013).

Chapter Summary

This chapter outlined the mixed methods research methodology used in this study. Quantitative data from the CIHI's DAD was analyzed to determine the characteristics of advanced-age adults who died in an acute care hospital in Ontario and the hospital care they received in the last hospital stay ending in death. This quantitative phase was needed to confirm or challenge the literature review findings, as it was necessary to determine if advanced-age older people die in hospital and if quality of EOL care issues could exist. Charmaz's grounded theory techniques were then used to develop a substantive theory of high-quality EOL care for advanced-age adults, with this theory entirely based on the perceptions of their adult children, although with this theory also having been informed by the various findings reported in the literature review. Sampling and recruitment procedures were outlined, and data collection and analysis were discussed. Chapter Three also integrated issues pertaining to ethical research conduct and outlined measures used to ensure research quality.

CHAPTER FOUR

RESEARCH FINDINGS

The findings of this mixed methods research regarding quality (EOL) hospital care for advanced-age adults are presented in two sections. First, the Canadian Institute of Health Information discharge abstract data (CIHI DAD) findings are presented on the demographic and health-related characteristics of advanced-age adults (aged 85+) who died in Ontario acute care hospitals during the 2014-2015 fiscal year, as well as information on their hospital utilization. This data analysis provided key information with which to plan and explore the qualitative responses during the second phase of this study. In the second section, findings from the grounded theory analysis of adult children perceptions of the quality of EOL hospital care received by their advanced-age parents are presented. Together, these findings lay that foundation for a substantive theory on high-quality EOL care for hospitalized advanced-age adults.

Quantitative Findings – CIHI DAD

Demographic and Health Characteristics of Advanced-Age Hospital Decedents

The first quantitative research question was: What are the socio-demographic and health-related characteristics of advanced-age adults (85+) who died in an acute care hospital in Ontario during the fiscal year of April 1st, 2014 through March 31st, 2015? Overall, 41,191 people died in Ontario acute care hospitals during the 2014–2015 fiscal year (see Table 6). Of these, 32.7% (13,450) were aged 85 and over. The majority (82.1%) of advanced-age hospital decedents died while receiving medicine (or non-surgical) services and also receiving palliative care (comfort care only) services (n = 9,339 and n = 1,700 respectively, for a total n of 11,039). In contrast, only 12.0% of advanced-age adults (n = 1,610) died in a specialty care unit (SCU) such as an intensive care unit (ICU) or step-down unit.

The advanced-age hospital decedents ranged from 85 to 113 years of age, with a median age of 89. A greater portion of these were female (55%), and the majority (86.2%) lived in urban areas. Ontario is comprised of 20 Local Health Integration Networks (LHIN) which are collectively responsible for the management and delivery of health care services in the province. The more heavily populated Central, East Central, and Hamilton Niagara Haldimand Brant LHIN regions had the highest proportion of advanced-age adult hospital decedents (12.3 %, 12.5%, and 11.7% respectively), while the sparsely populated North West LHIN region had the fewest advanced-age decedents (2.0%). Only 30.2% (n = 4,066) of advanced-age hospital decedents were admitted from nursing homes and homes for the aged, with 64.1% of advanced-age hospital decedents admitted from private residences.

The CIHI DAD did not capture marital status or ethnic background. However, select other demographic and health-related characteristics of advanced-age decedents were compared according to the decedent's main patient service at the time of death. Kruskal Wallis tests (*H*) and chi-square tests (X^2) indicated that age, gender, and urban residence significantly differed depending on the main patient service (H [3, $N = 13398$] = 221.28, $p < .05$; X^2 [3, $N = 13398$] = 31.92, $p < .05$; X^2 [3, $N = 13316$] = 188.13, $p < .05$ respectively). Post hoc Bonferroni analyses demonstrated that advanced-age decedents in the medicine group were significantly older than those dying in a SCU (H [1, $N = 10949$] = 198.69, $p < .0167$). No differences in age were found between the medicine group and the surgical or palliative care groups (H [1, $N = 10088$] = 2.79, $p > .0167$; H [1, $N = 11039$] = 3.59, $p > .0167$ respectively). The medicine group had significantly less advanced-age decedents living in urban residences than all other groups, while the SCU group had significantly more male advanced-age decedents than the other three groups.

The top six disease chapters representing common most responsible diagnoses (MRDx) for all advanced-age hospital decedents were: (a) diseases of the circulatory system (22.5%); (b) factors influencing health status and contact with health services (22.0%); (c) diseases of the respiratory system (19.0%); (d) certain infections and parasitic diseases (8.2%); (e) injuries, poisoning, and other external causes (5.8%); and (f) diseases of the digestive system (5.6%). Following these, neoplasms accounted for only 4.7% of decedent MRDxs (see Table 6). Of all decedents who had a MRDx of factors influencing health and health services, 97.6% also had a MRDx of palliative care (Z515). At the disease level, other MRDx of note were heart failure (I50, 8.2%), sepsis (A41, 6.6%), pneumonia (J18, 6.0%), pneumonitis due to aspirated solids and liquids (J69, 4.3%), acute myocardial infarction (I21, 4.3%), cerebral infarction (I63, 3.8%), and chronic obstructive lung disease (COPD) (J44, 4.2%).

Table 6
Demographic and Health Characteristics of Hospitalized Advanced-Age Decedents

Item		**Total 85+** N = 13450	**Medicine** N = 9339	**Surgery** N = 749	**Palliative Care** N = 1700	**SCU** N = 1610	***p* value** N = 13398
Total Numbers		13450 (100%)	9339 (69.45%)	749 (5.57%)	1700 (12.64%)	1610 (11.97%)	
Age							
	Median	89.0	89.0_a	90.0_a	90.0_a	88.0_b	$H(3) = 221.28$ $p < .05$
	Range	85-113	85 - 110	85 - 113	85-105	85-105	
Gender							
	Male	6050 (45%)	$4210(45.1\%)_a$	$302\ (40.3\%)_a$	$711\ (41.8\%)_a$	$810\ (50.3\%)_b$	$X^2(3) = 31.92$, $p < 0.05$
	Female	7400 (55%)	5129 (54.9%)	447 (59.7%)	989 (58.2%)	800 (49.7%)	
Urban		11595 (86.2%)	$7825\ (84.3\%)_a$	$670\ (90.2\%)_b$	$1610\ (94.9\%)_c$	$1457\ (91.5\%)_b$	$X^2(3) = 188.13$ (N=13316) $p < 0.05$
Transferred from							
	Nursing Home & Home for Aged	4066(30.2%)	$3029(32.4\%)_a$	223(29.8%)a	$538(31.6\%)_a$	$266(16.5\%)_b$	$X^2(15) = 309.47$,

Acute Care facility	442 (3.3%)	277(3.0%)$_{a,b}$	35 (4.7%)$_{b,c}$	43 (2.5%)$_{a}$	78 (4.8%)$_{c}$	$p < .001$
Other facility	321 (2.4%)	207 (2.2%)$_{a}$	16 (2.1%)$_{a}$	41 (2.4%)$_{a}$	53 (3.3%)$_{a}$	
Outpatient/Day surgery	589 (4.4%)	321 (3.4%)$_{a}$	80 (10.7%)$_{b}$	67 (3.9%)$_{a}$	119 (7.4%)$_{c}$	
Home Care	146 (1.1%)	119 (1.3%)$_{a}$	6 (0.8%)$_{a, b}$	14 (0.8%)$_{a, b}$	5 (0.3%)$_{b}$	
Home without Home Care	7886 (58.6%)	5386 (57.7%)$_{a}$	389(51.9%)$_{b}$	997 (58.6%)$_{a}$	1089(67.6%)$_{c}$	
MRDx chapter‡						
Circulatory D (IX)	3020 (22.5%)	2428 (26.0%)	52 (6.9%)	382 (22.5%)†	536 (33.3%)	
Respiratory D (X)	2560 (19.0%)	2192 (23.5%)	37 (4.9%)	316 (18.6%)†	323 (20.1%)	NA
Infections (I)	1109 (8.2%)	872 (9.3%)	17 (2.3%)	113 (6.6%)†	216 (13.4%)	
D of GU (XIV)	559 (4.2%)	523 (5.6%)	-- (0.-%)	105 (6.2%)†	33 (2.0 %)	
Neoplasms (II)	635 (4.7%)	538 (5.8%)	48 (6.4%)	344 (20.2%)†	46 (2.9%)	
Digestive D (XI).	752 (5.6%)	494 (5.3%)	112 (15.0%)	101 (6.2%)†	144 (8.9%)	
Injuries (XIX).	786 (5.8%)	242 (2.6%)	405 (54.1%)	61 (3.8%)†	138 (8.6%)	
Factors influencing health/health service (XXI)	2961 (22.0%)	1134 (12.1%)	37 (4.9%)	1670 (98.2%)‡	71 (4.4%)	
Palliative Care as MRDx:	2837 (21.1%)	1037(11.1%)$_{a}$	34 (4.5%)$_{b}$	1668 (98.1%)$_{c}$	71 (4.4%)$_{b}$	X^2 (3)= 7041.40
Known palliative plan	491 (17.3%)*	196 (18.9%)*	--	278 (16.7%)*	5 (7.0%)*	$p < .05$
All Palliative Care Dx	8443(62.8%)	5621(60.2%)$_{a}$	389(51.9%)$_{b}$	1682 (98.9%)$_{c}$	711(44.2%)$_{d}$	X^2 (3)= 1253.86
Known palliative plan	629 (7.4%)*	322 (5.7%)*	7 (1.8%)*	281 (16.7%)*	11 (1.5%)*	$p < .05$

MRDx ‡ = Most responsible diagnosis by ICD-10 diagnostic code by chapter; †= Second listed ICD -10 diagnosis code by chapter; * = % of decedents with a palliative diagnosis that were also known to have a palliative plan prior to admission. -- = < 5 cases. Each subscript letter indicates a subsection of Main Patient Service group whose columns do not differ from one another at p < .05 level of significance (IBM Corp, 2015). NB: Advanced-aged decedents not included in grouped calculations = 52 admitted under ALC only, rehab, & psychiatry units. Abbreviations: D = Disease; GU = genitourinary; Dx = diagnosis.

Palliative Care as MRDx Diagnosis among Advanced-Age Hospital Decedents

The second quantitative research question was: What was the percentage of hospital decedents aged 85+ who were designated as having a palliative diagnosis (ICD 10 code, Z515)? In total, only 2,837 (21.1%) advanced-age decedents had palliative care listed as their MRDx. Among these decedents, palliative care was the only diagnosis identified for six decedents (0.2%). Of all 2,837 decedents who had palliative care listed as the MRDx, 17.3% had a known palliative care plan prior to hospitalization as indicated by the diagnostic code prefix 8. As expected, significantly smaller proportions of advanced-age decedents were assigned the MRDx of palliative care in the medicine (11.1%), surgery (4.5%), and SCU (4.4%) groups as compared to the palliative care group [(98.9%), X^2 (3) = 7041.40, $p < .05$]. When all 25 diagnostic coding variables were examined, the proportion of advanced-age decedents with a palliative care diagnosis increased to 62.8% overall and 60.2% for the medicine group. The latter findings indicate that advanced-age adults either received treatment for reversible conditions or transitioned to palliative care during the course of the final hospital stay.

Hospital Use Characteristics of Advanced-Age Hospital Decedents

The third quantitative research question addressed was: What was the pattern of hospital use in relation to variables such as length of stay (LOS) and the percentage of alternative level of care (ALC) days among older decedents aged 85+? Advanced-age decedent hospital use during the final hospital stay was analyzed according to the type of entry to hospital, the type and size of hospital according to peer group, the total length of stay (LOS) in days, and the number and percentage of alternative level of care (ALC) days (see Table 7).

The vast majority of advanced-age hospital decedents (91.3%, n=12,283) were admitted through an emergency room while only 8.1% were directly admitted to an inpatient hospital bed from the community. The remaining 0.5% of advanced-age decedents were admitted from other locations, such as a medical clinic. A significantly smaller proportion of advanced-age decedents were directly admitted to hospital in the medicine group (6.2%) as compared to the surgical, palliative care, and SCU groups (13.0%, 10.3%, and 13.4% respectively; [X^2 (6, N = 13398) = 174.56, $p < .05$]).

This study revealed that most advanced-age decedents died in small community hospitals (47.4%, n = 6374), followed by teaching hospitals (24.1%, n = 3247), with smaller proportions of decedents dying in medium and large hospitals (19.8%, n = 2658 and 8.7%, n = 1169 respectively). A significant portion of decedents categorized as receiving palliative care services died in small hospitals as compared to those dying while receiving care from medicine and surgery services, and SCU units, (X^2 [9, N = 13398] = 881.81, $p < .05$).

Overall, advanced-age decedents had a mean LOS of 12.3 days (SD±21.8) and a median stay of 6.0 days. Over half (56.1%) died within one week of admission to hospital, 75.5% within two weeks of admission, and 90.1 % within one month of admission. Similarly, 74.4% of medicine decedents died within two weeks of hospital admission and 90.9% within one month of hospital admission. Statistically significant differences were found when comparing median LOS days between the medicine, surgical, palliative care, and SCU groups (H [3, N = 13398] = 283.27, $p < 0.05$). Advanced-age decedents in the medicine group had significantly longer median LOS days (7 days) than the palliative care (6 days) and SCU groups (3 days), and shorter median LOSs than the surgery group (8 days).

The percentage of ALC days is a common indicator used to describe the percentage of in-patient days that a patient occupies an acute care hospital bed after the patient has completed the acute phase of his/her treatment (Ministry of Health & Long Term Care, 2017). The percentage of ALC days is calculated by summing the total number of ALC days and dividing this sum by the total sum of LOS days (Ministry of Health & Long Term Care, 2017). Higher percentages are generally reflective of insufficient community supports, such as long-term care beds or home care services (CIHI, 2009). Overall, ALC days accounted for 22.6% of advanced-age hospital decedent total days in hospital. However, 85.0% of all hospitalized advanced-age decedents had no ALC days. The percentages of ALC days varied from a high of 26.0% for advanced-age decedents who died receiving care on a medicine service to a low of 4.1% for advanced-age decedents who died in a SCU. As predicted, statistically significant differences were found between the medicine, palliative care, and SCU groups (X^2 [3, N = 13398] = 369.78, $p < .05$).

Post-hoc Bonferroni tests demonstrated no difference in median ALC days between medicine and surgical services; however, the medicine group had significantly more ALC days as compared to the palliative care and SCU groups.

Table 7

Hospital Use Characteristics among Hospitalized Advanced-Age Decedents

Item	**Total 85+** N = 13450	**Medicine** N = 9339	**Surgery** N = 749	**Palliative Care** N = 1700	**SCU** N = 1610	***p* value** N = 13398
Entry to hospital:						
Direct Admit	1095 (8.1%)	582(6.2%)$_a$	97(13.0%)$_{b,c}$	175(10.3%)$_c$	216(13.4%)$_b$	X^2 (6) =
Emergency Room	12283(91.3%)	8725(93.4%)$_a$	642(85.7%)$_{b,c}$	1515(89.1%)$_c$	1374(85.3%)$_b$	174.56 $p < .05$
Other	72 (0.5%)	32(0.3%)$_a$	10(1.3%)$_b$	10(0.6%)$_{ab}$	20(1.2%)$_b$	
Hospital Type						
Small C-H1	6374 (47.4%)	4055(43.4%)$_a$	306(40.9%)$_a$	1224(72%)$_b$	780(48.4%)$_c$	X^2 (9) =
Medium C-H2	2658 (19.8%)	2024(21.7%)$_a$	130(17.4%)$_b$	253(14.9%)$_b$	235(14.6%)$_b$	881.81
Large C-H3	1169 (8.7%)	1059(11.3%)$_a$	8(1.1 %)$_b$	44(2.6%)$_b$	38(2.4 %)$_b$	$p < .05$
Teaching- T	3247 (24.1%)	2201(23.6%)$_a$	305(40.7%)$_b$	179(10.5%)$_c$	557(34.6%)$_d$	
LOS days						
Mean	12.3(SD 21.8)	12.8(SD 22.4)	15.8(SD 22.0)	11.0(SD 17.7)	8.9(SD 20.2)	
Median	6.0	7.0$_a$	8.0$_b$	6.0$_c$	3.0$_d$	H(3)= 283.27
Range	1 – 688	1 – 688	1 – 214	1 – 330	1 – 368	$p < .05$
1 – 3 days	4567 (34.0%)	2984 (32.0%)	175 (23.4%)	588 (34.6%)	807 (50.1%)	
4 – 7 days	2978 (22.1%)	2045 (21.9%)	174 (23.2%)	423 (24.9%)	328 (20.4%)	
8 – 14 days	2612 (19.4%)	1917 (20.5%)	153 (20.4%)	289 (17.0%)	240 (14.9%)	
15 – 30 days	2128 (15.8%)	1543 (16.5%)	145 (19.4%)	280 (16.5%)	151 (9.4%)	
31+ days	1165 (8.6%)	850 (9.1%)	102 (13.7%)	120 (7.1%)	84 (5.2%)	
ALC days						
% ALC days	22.56 %	26.06%	21.24%	9.93%	4.12%	
Mean	2.78(SD 15.2)	3.34(SD 16.7)	3.36(SD 13.8)	1.09(SD 8.96)	0.37(SD 4.33)	
Median	0	0	0	0	0	
Range	0 - 681	0 – 681	0 – 208	1 – 273	0 - 97	X^2 (3)
0 days	11436 (85%)	7655(82.0%)$_a$	624 (83.3%)$_a$	1576(92.7%)$_b$	1579(98.1%)$_c$	=369.78
1 – 3 days	538 (4.0%)	459 (4.9%)	25 (3.3%)	34 (2.0%)	7 (0.4%)	$p < .05$
4 - 7 days	421 (3.1%)	348 (3.7%)	24 (3.2%)	34 (2.0%)	7 (0.4%)	
>7 days	1055 (7.8%)	877 (9.4%)	76 (10.1%)	56 (3.3%)	17 (1.0%)	

Each subscript letter indicates a subsection of the Main Patient Service groups whose columns do not differ from each other at the $p < .05$ level of significance (IBM Corp, 2015). NB: Advanced-aged decedents not included in grouped calculations = 52 admitted under ALC only, rehab, & psychiatry units. Abbreviations: C = Community hospital; LOS = Length of stay; ALC = Alternative level of care.

Use of Life-sustaining Treatment among Advanced-Age Hospital Decedents

The fourth research question was: What types of life-sustaining treatment did advanced-age decedents (aged 85+) receive during their final hospital stay ending in death? The life-sustaining treatments examined were cardiopulmonary resuscitation (CPR), mechanical ventilation, dialysis, chemotherapy, blood transfusion, admission to a SCU, and death in a SCU (see Table 8). Overall, 21.2% (n = 2,852) advanced-age decedents were admitted to a SCU during their final hospital stay, while 12.0% (1,610) died in a SCU. A higher proportion of urban-dwelling advanced-age decedents died in SCUs (91.5%) as opposed to their rural counterparts (8.5%).

Overall, only 3.2% (425) of advanced-age decedents underwent CPR at some point during their final hospital stay. Significantly smaller proportions of advanced-age decedents were administered CPR while receiving medicine (1.8%) or palliative care (0.3%) services as compared to decedents receiving surgical services or care in a SCU, (X^2 [3, N = 13398] = 702.19, p < 05). In addition, 11.4% (n = 1,539) of advanced age decedents received mechanical ventilation during their final hospital stay ending in death, 1.6% (n = 218) had dialysis, and 1.1% (n = 151) received chemotherapy. Using the blood transfusion flag, 15.4% (n = 2,071) of all advanced-age decedents had a blood transfusion during their terminal hospital stay. Significantly smaller proportions of decedents receiving medicine (12.5%) and palliative care services (5.4%) had blood transfusions, as compared to decedents receiving surgical services (36.4%) or care in a SCU (33.4%), (X^2 [3, N = 13398] = 846.83, p < 05).

Table 8:
Life-sustaining Treatment Provided to Hospitalized Advanced-Age Decedents

Item	**Total 85+** N = 13450	**Medicine** N = 9339	**Surgery** N = 749	**Palliative Care** N = 1700	**SCU** N = 1610	***p* value**
CPR	425 (3.2%)	164 (1.8%)$_a$	34 (4.5%)$_b$	5 (0.3%)$_c$	222 (13.8%)$_d$	X^2 (3)= 702.19 $p < .05$
SCU admission	2852 (21.2%)	971 (10.4%)$_a$	209 (27.9%)$_b$	63 (3.7%)$_c$	1610 (100%)$_d$	X^2 (3) = 6945.72 $p < .05$
Artificial Respiration	--	--	0	0	0	*NA*

Mechanical Respiration	1539 (11.4%)	453 (4.9%)$_{a}$	109 (14.6%)$_{b}$	34 (2.0%)$_{c}$	943 (58.6%)$_{d}$	X^2 (3)= 4072.49 $p < .05$
Dialysis	218 (1.6%)	125 (1.3%)$_{a,b}$	14 (1.9%)$_{b}$	10 (0.6%)$_{a}$	68 (4.2%)$_{c}$	X^2 (3) = 84.79 $p < .05$
Chemotherapy	151 (1.1%)	94 (1.0%)$_{a}$	8 (1.1%)$_{a,b}$	15 (0.9%)$_{a}$	34 (2.1)$_{b}$	X^2 (3)= 16.16 $p < .05$
Blood Transfusion	2071 (15.4%)	1166(12.5%)$_{a}$	273 (36.4%)$_{b}$	91 (5.4%)$_{c}$	538 (33.4%)b	X^2 (3) = 846.83 $p < .05$

CPR = Cardiopulmonary resuscitation, SCU = Specialty care unit.
Each subscript letter indicates a subsection of Main Patient Service group whose columns do not differ from each other at the $p < .05$ level of significance (IBM Corp, 2015). -- = < 5 cases. NB: Advanced-aged decedents not included in grouped calculations are 52 admitted under ALC only, rehab, & psychiatry units.

Unique Characteristics of Advanced-Age Hospital Decedents Receiving Medicine Services

To identify unique characteristics of decedents who died in hospital while receiving care from a medicine (non-surgical) service as compared to non-medicine decedents, a logistic regression analysis was performed using the variables: Age, gender, urban residence, area transferred from, hospital type, MRDx, LOS, ALC days, and variables related to life-sustaining treatment (see Table 9). In the logistic regression analysis, advanced-age decedents on a medical service showed several unique characteristics at the $p < .001$ level of significance as compared to non-medicine advanced-age decedents. Medicine decedents were slightly older in age (Mean age 90.0 vs. 89.6), had longer lengths of stay (median 7 days vs. 5 days), and had a higher percentage of ALC days (26.1% vs. 13.5 %) as compared to non-medicine decedents. Medicine advanced-age decedents also were more likely to be transferred from a nursing home or a home for the aged (32.4% vs. 25.2%) as compared to non-medicine decedents. The most responsible diagnoses which characterized medicine patients at the $p < .001$ significance level in order of likelihood included disorders of the urinary system (64x), pneumonitis (8.7x), acute renal failure

(7.7x), pneumonia (7.5x), cerebral infarction (6.2x), heart failure (5.8x), COPD (4.2x), sepsis (2.8x), and acute MI (2.2x). This logistic regression model accounted for 28.1% of the variance.

Table 9
Characteristics of Advanced-Age Adults who Died on Medicine (Non-Surgical) Hospital Units

			95% Confidence Interval		
	B (S.E.)	Exp(B)	Lower	Upper	P Value
Constant	.180(.150)	1.197			0.232
Median Age	.224 (.043)	1.252	1.150	1.362	.000
Male	.015 (.043)	1.052	.933	1.104	.793
Urban	-.232 (.091)	.793	.654	.947	.011
NH/Home for Aged	.374 (.118)	1.453	1.153	1.832	.002
Acute Care Transfer	-.436 (.159)	.647	.474	.884	.006
Ambulatory Care	-.552 (.148)	.576	.431	.759	.000
No Transfer	-.035 (.114)	.965	.772	1.207	.756
Median LOS	.149 (.045)	1.161	1.063	1.268	.001
Median ALC	1.044 (.074)	2.841	2.455	3.286	.000
Small Community H1	-.315 (.053)	.729	.658	.809	.000
Medium Community H2	.245 (.068)	1.277	1.117	1.461	.000
Large Community H3	1.408 (.132)	4.088	3.156	5.294	.000
Sepsis	1.021 (.086)	2.776	2.344	3.288	.000
Acute MI	.786 (.101)	2.194	1.799	2.676	.000
Cardiac Arrest	-.321 (.241)	.726	.452	1.164	.183
Heart Failure	1.759 (.100)	5.808	4.777	7.062	.000
Cerebral Infarction	1.827 (.146)	6.212	4.670	8.264	.000
Pneumonia	2.020 (.127)	7.538	5.873	9.677	.000
COPD	1.435 (.126)	4.198	3.278	5.376	.000
Pneumonitis	2.166 (.153)	8.720	6.456	11.779	.000
Respiratory Failure	.461 (.137)	1.586	1.213	2.075	.001
Acute Renal Failure	2.038 (.199)	7.677	5.196	11.343	.000
Disorder of Urinary Sx	4.172 (.713)	64.839	16.040	262.107	.000
Intracranial Injury	-.085 (.165)	.918	.664	1.270	.607
Fractured Femur	-2.473 (.163)	.084	.061	.116	.000
Malignant Neoplasm	1.405 (.120)	4.076	3.223	5.155	.000

Omnibus Test of Model Coefficients: $X^2(25, N = 13365) = 2963.31, p < .001$;
Hosmer & Lemeshow Test $X^2(8df) = 7.056; p = .531$.
Model Summary: -2 Log Likelihood = 13482.8; Nagelkerke R Square = .281

Qualitative Findings

The following section presents the results of the qualitative portion of the study. First, the sample of adult children interviewed is described. Second, a contextual overview is provided, outlining the advanced-age parent demographic profile as well as the parent illness and death trajectories as gleaned from interviews and demographic questionnaires. Adult children's ratings of the quality of EOL care received are also highlighted. Third, a detailed description is provided regarding the four identified themes surrounding adult children's perceptions of high-quality EOL care for their advanced-age parents, and fourth, a description of the substantive theory of high-quality EOL care is presented. The names of the participants have been changed to ensure confidentiality.

Sample – Adult Children

In total, 15 children were interviewed about 12 advanced-aged parents who received EOL hospital care in 7 hospitals in Southern Ontario. Interviews with adult children took place within a median of 6 months of their parent's death. The children's ages ranged from 53 to 79 (median 60). Eleven (73.3%) participants were female, 40.0% had undergraduate degrees or higher degrees, 53.3% were working in full or part time positions, and 60.0% were married or partnered. The majority (66.7%) had shared the care of their dying parent with one or more siblings.

The Parents

The median age of parents was 89 years ($X = 91$years). Six parents were female and six were male. The vast majority of parents were widowed (75%). Six parents lived in their own home, one parent lived with family, and two parents lived in a retirement home. Only three parents lived in a nursing home prior to their final hospital stay.

Many parents were described as having increased care needs immediately prior to the terminal hospitalization. More specifically, 75% of parents were described as being mostly dependent on others for their activities of daily living, thus requiring assistance with bathing and dressing for around two weeks before their final hospital stay. Seven parents were reported to have had an increased use of health services prior to their final hospital stay. Of these, one parent visited the emergency room every 10 to 15 days during the last 3 months of life because of breathing difficulties. Five parents had at least one previous hospital stay in the preceding year, and one parent had 7 admissions to hospital in the 6 months preceding death.

At least four parents, however, were described as being quite well until one day or as much as one week before hospitalization. One parent was able to drive to and from his favorite coffee shop one week prior to his final hospital stay. Another parent in her centennial years lived in her own apartment with the periodic help of community resources. In this case, hospitalization was not required until she fell and fractured her leg. Parents were said to be admitted to hospital for a variety of reasons relating to urinary tract infections or pneumonia (n = 6), congestive heart failure/bradycardia (n = 4), cancer (n = 3), and injuries due to a fall (n = 2). All of the final hospital stays described began with a visit to the emergency room.

Common interventions that parents received during their final hospital stay included intravenous fluids, antibiotics, and oxygen. Two parents required oral suctioning. Two parents with sepsis were admitted to an intensive care unit and were later transferred to a medical or palliative care unit where they died. No parent received CPR. The majority of parents had a do not resuscitate (DNR) order in place well in advance of the death. One parent's code status changed to DNR after a crisis occurred and a family meeting was subsequently held.

Most adult children (75%) reported their parent died within 1 or 2 weeks of their admission to hospital. Two of the parents declined in health and died quickly, and they also died with little warning that death would occur. For example, one parent was admitted with bradycardia and died the next day. In contrast, two parents died after being in hospital for about one month, during which time they received active treatment to attempt to reverse the admitting health problem.

Only 2 of the 15 adult children were aware in advance of the hospital admission that their parent would likely die during the last hospital stay. These two participants advocated for a hospital death instead of a home death to ensure their parent received good EOL pain control. When adult children became aware of the impending death, for most (11/13), the impending death was a surprise. Seven participants (46.9%) knew their parent would die 1 to 3 days prior to the death, two (13.4%) knew this 4 to 7 days prior to death, and four (26.8%) knew this 8 or more days before their parent's death. For instance, Kelly commented on the element of surprise associated with her parent's death:

> *Well…Grammy's brother was 95 [and Grammy's brother said], 'Why don't you ask for palliative care.' And I said and I was a little shocked that he mentioned it because… it meant he was acknowledging that she was gonna die. We …really didn't know that [Grammy would die] at all.*

The fact that some advanced-age parents recovered after previous illnesses contributed to uncertainty among many participants about their parent's final illness and hospitalization. Debra said, "I wasn't sure, but each time I was fearful that something could happen, 'cause she was pretty sick, and then she'd bound back…just enough to get her home."

Adult children varied in the amount of caregiving they provided to their parent during the final hospitalization. Three participants spent many hours, day and night, with their parent during their parent's final hospital stay. Seven adult children provided hands-on care, while eight others mainly provided emotional support. Other participants provided support when they could, but were required to balance caregiving responsibilities with work responsibilities. Most participants visited daily, then helped to maintain constant vigil when the parent's death was imminent.

When able, some families shared care with other family members in maintaining a rotating but overall bedside vigil.

All adult children described their parents as receiving both high-quality and low-quality care during the last hospital stay. Overall, children rated the quality of EOL hospital care quite positively. When asked "how would you rate the overall hospital care received by your parent at the end of his/her life?" on a visual analogue scale from 0 (extremely poor - worst possible) to 10 (outstanding – couldn't be better), 14 of the 15 adult children gave a median rating of 7.5 (range: 0 – 10; mode: 9). One (Candice) chose not to rate the hospital care received, explaining, "It's not an integer…" She said the first three days of care were exceptional, while the last three days, after her parent was transferred to a different unit, were below her expectations. A similar difference in the quality of care over the last hospital stay was also evident among other participants. For example, two participants, whose parents were transferred from one hospital to another, rated the quality of care received at the first hospital as poor and praised the care received at the second hospital.

Identified Themes

Four themes were identified through the data analysis: (a) *being an adult child,* (b) *being an advocate*, (c) *receiving high (or low) quality care at the end of life*, and (d) *reacting and remembering*. The first two themes *being an adult child* and *being an advocate* were contextual. Both themes affected the adult child's perception of the quality of end-of-life care received by their parent in hospital, including the children's resulting emotional reactions and memories of the care received. The third theme, *receiving high (or low) quality care at the end of life*, had four opposing sub-themes (or categories): (a) *being kept informed versus being left in the dark*, (b) *receiving compassionate care versus being treated uncaringly*, (c) *being treated with dignity* *and respect versus being devalued as a person*, and (d) *receiving optimal care and comfort versus falling through the cracks.* The fourth theme, *reacting and remembering*, represents the consequences of the quality of EOL care that their parent received.

Theme 1 - Being an adult child. The theme *being an adult child* embodies the sense of responsibility, and the values and expectations that these adult children had when their dying parent was receiving care in hospital. This sense of responsibility is what motivated adult children to behave and advocate the way he or she did. This theme consists of four sub-themes (or categories).

Sub-theme 1.1 - Being worried and concerned. Adult children often tried to make sense of things through wondering about the cause of the illness. Moreover, in the midst of the uncertainty of their parent's illness, they often felt helpless. Cathy, whose parent was waiting to be seen in the emergency room before dying in the hospital later that week said, "He was just screaming, 'Help me!' Over and over again. And I couldn't settle him" She then continued, "It was really upsetting...because I didn't know what was going to happen. And I was really worrying about him...Like– he was really in distress."

Sub-theme 1.2 - Feeling a strong sense of responsibility. All adult children felt a strong sense of responsibility in relation to ensuring their parent received the care that was required to meet their parent's needs. Motivated by this sense of responsibility, they acted as their parent's protector, voice, and/or supervisor of care. Debra said, *"*I guess I felt responsible for some of it, too…Like it was up to me to make sure everything was done…I felt sure they were going to miss something." Kate echoed the sense of responsibility, "They're obviously not able to speak for themselves, so somebody… has to…And…boy, you sure do want to try and get them the best care you possibly can, right? There's tons of responsibilities."

Adult children reported feeling responsible to help facilitate decisions regarding their parent's treatment and plan of care while in hospital. Cathy said, "And, that's when it got tricky. Because then I had to decide whether to try and do brain surgery on a 99 year old." Their ability to meet this responsibility was thought to depend on whether or not they had sufficient information to make decisions about treatment, the plan of care, or about transitioning to care needed for the end of life.

Sub-theme 1.3 – Values and expectations. Most adult children expected the EOL care in hospital to be of a certain quality; such as good personal care, pain control, and treatment according to the parent's needs and wishes. The type of care differed depending on the goals of care at the time; active treatment to improve reversible illnesses or comfort care at the end of life. Debra expressed her concern, "That she got good care, that, you know, that they did everything they could to diagnose what was going on, and then treat within the ability of her health." Quality care for others meant receiving good older person care, including how to communicate with patients affected by delirium or dementia and mobilizing patients to prevent deconditioning. Barbara emphasized that quality of EOL care meant:

> *Still making sure that their needs are met. That just because it's end-of-life care, it doesn't mean you stop turning them, you stop feeding, you stop asking them if they need anything, [or] stop giving them something for pain or asking if they're uncomfortable.*

Adult children's values and expectations regarding quality care were influenced by their past experiences of working in health care and/or having experience with palliative care. For example, participants who worked in health care settings had higher expectations of what quality care should be, and they compared these expectations to the care their parent actually received.

Many participants also reflected upon their past experiences of the EOL care provided to other dying family members. For example, George talked of his wife who had died years ago in palliative care, “On morphine, comfortable, and relaxed.”

Sub-theme 1.4 – Balancing competing demands. Often the adult children balanced competing demands on their time and energy as their parent was dying. Over half of adult children continued working while caregiving and providing practical support for their parent when their parent was in hospital. Two participants were required to care for more than one older parent at the same time; both participants took leave of absences from work to care for their hospitalized parent. Danielle indicated, “It was a big decision for me even to take those leaves of absences, but I had to because….my sister was retired, but…I couldn’t leave that burden all on her.”

Theme 2 - Being an advocate. The theme *being an advocate* encompassed the activities associated with ensuring their parent’s needs were addressed. Trish described the role of the adult child, “You have to be there for them. You have to be their voice. If you see something that’s not right, be their voice and find out the answers.” Trish continued, “And respect their wishes, and if she chose not to have any more treatments, that’s their choice.”

The type of care that participants advocated for depended on their awareness of the closeness of death and their expected focus of the hospital care. For example, one participant advocated for the code team to be called when she did not fully understand her parent’s illness, while another participant who was fully aware that their parent would die, advocated for a transfer to a palliative care service. Many participants acted as coordinators of care; they received information from health providers, relayed information to family members, and supported their parent with decisions regarding the parent’s treatments and plan of care. Five participants suggested care options, such as referrals to other services. When parents were not able to make decisions for themselves, their children made care decisions for them based on their knowledge of their parents' wishes. Barbara for instance also acted as a family advisor and supported family members surrounding EOL care decisions for her parent-in-law:

> *And the physician said, 'You know, the antibiotics don't seem to be working; we may have to do some additional treatment type things.' And they all looked at me and said, 'Well, what should we do?' And I said, 'Well, he didn't want anything invasive. He didn't want invasive lines and he didn't want blood pressure medication and all that kind of stuff. And he didn't want resuscitation.' And I said, 'This decision is up to the three of you. But I think we should keep him comfortable.' And they all kind of all agreed, and so that's what we did.*

As advocates, adult children needed support, reassurance, and acknowledgement from the hospital staff. Danielle shares her experience when her parent died suddenly, "I think I said to [the nurse], 'I don't even know where to start'…She said, take your time, we'll help you through this, like you know, she was very good about that."

Theme 3 - Receiving high (or low) quality care at the end of life. The theme *receiving high (or low) quality care at the end of life* was composed of several overlapping sub-themes. Adult children described high-quality EOL care as occurring when they were kept informed, when their parent was receiving optimal care and comfort, and when they and their parent were being treated with compassion, and also treated with dignity and respect. In contrast, low quality EOL care was described when they were kept in the dark, when their parent was receiving poor or uncoordinated care ("falling through the cracks"), or when they and their parent were being treated uncaringly or being devalued as a person.

Sub-Theme 3.1 - Being kept informed vs. being left in the dark. Receiving information regarding their parent's condition was key for adult children to understand their parent's illness and help make care decisions that were in line with their parent's wishes. Adult children varied on the degree of information they required; a high need for information occurred in the emergency room and then also later on the unit when there was a high degree of uncertainty related to the illness. Information was needed to help adult children to reframe realities surrounding the illness, increase their awareness about their parent's impending death, and transition their parent's care from curative care to EOL care.

Adult children described conditions that worked to keep them informed. These included being informed about changes in their parent's condition; being given timely, honest, and clear information about their parent's condition including findings of tests; being informed about prognosis; and being kept up-to-date regarding how their parent was doing on a day-to-day basis. Nurses and physicians were their primary sources of information. When adult children were kept informed, they were able to balance care options with their parent's previous wishes and increase their confidence about the care decision made. For instance, Cathy, whose parent sustained a head injury after a fall, explained:

> *When my dad was hallucinating,..[The doctor] took the time to sit down and talk with me, have a conversation about what was happening. Still saying it was my decision. But, you know...he kinda gave me the confidence to make my decision...And then, he said, 'I'm gonna move him to the palliative care room.' And I thought, 'That's brilliant. That's so good.'*

Physicians also helped adult children to gain perspective and clarify expectations about their parent's illness. Two participants explained, "And [the doctor] called the family meeting and he explained everything to us, that he was palliative…He explained detail to detail" (Karen). "Stopped all medicine, just comfort measures from then on." (Rachel).

Adult children valued receiving updates from nurses regarding their parent's condition and explanations of the dying process. They also were very appreciative of being called when their parent's death was imminent. Receiving this warning meant that family members were given the choice to be present at the time of death. For instance, Dan explained, "And the thing I remember most was them keeping me informed about how she was doing. I thought that was very nice...every time they saw me, we would talk about...how she was, whether she was eating or not." Dan continued, "I really appreciated them giving us the warning about how close she was to the end." When the parent's death occurred suddenly without warning, children appreciated hearing about the quality of death. Danielle recalled, "Very quick. Very peaceful. They said it was very peaceful."

Creating a space for communication was important. Family meetings were a valued venue for information sharing as they enabled family members to hear the same information from hospital staff and, together, provide input to the parent's plan of care. Two participants said, "That was the best" (Karen). "Then we all heard it. We all knew what was going on. We're all on the same page. And then we could…plan for Dad" (Rachel). One family had a meeting when the physician team entered the parent's hospital room to assess the parent. Another family had an impromptu family meeting when the parent's condition worsened and a transfer to ICU was being considered. In two cases, additional family members joined in the family meeting by teleconference. A family meeting did not occur for all parents. However, as long as adult children received the information they needed from the physician, they were generally satisfied.

Receiving information regarding the dying process also helped participants to know what to expect. Cathy reported:

> *I got the Stages of Dying [pamphlet], so I could recognize them. And yes, he followed them step by step...and then information on, you know, grief counselling. I had a very good package of that sort of thing…After reading the stages and the markers that someone is getting ready to die, I realized, yeah, I saw quite a few of those. I recognized them then. So that was helpful.*

In contrast to being kept informed, several adult children described situations that contributed to the sense of being left in the dark. Some participants described having difficulty gaining information about their parents' condition, seeing a doctor, finding out about test results, and finding a nurse who knew their parent's situation well. Adult children experienced a heightened sense of worry about their parent and an increased need for information when there was a significant change in their parent's health, especially when the adult child was not yet aware of the end of life nature of the parent's illness. As a result of not receiving needed information, two adult children reported being unable to actively participate in decision making for their parent. Had they known that the end of life was approaching, the children may have advocated for fewer tests and procedures, and an opportunity to spend quality time with their parent. Rachel indicated:

> *"And – we never, ever, ever got an answer. We never got told what was wrong. You know, his heart's too weak… They just said, 'We're looking into it.'.... I don't know. Maybe if – if we would have got more information on what the test was for, and the results, maybe we could have had that judgement and say, 'Okay, that's enough…If this was gonna be the end of life, then let's just leave him at peace… Don't put no*

> *more picc-lines, don't put nothing in him at any point." She continued, "If that was our choice, I would have kept him at home."*

Some physicians were described as being barriers to communication. At times, physicians were described as either not visible or hard to find. Trish explained, "I had a hard time seeing a doctor…I guess they don't have a specific schedule." Others physicians were described as not informing family about test results.

Nurses therefore played an important role in providing information and coordinating care. Barriers arose when nurses did not know the plan of care, results of test, or the timing of when the doctor would round. Kate waited several days to learn about test results and that date of a planned procedure, "We were just kind of sitting waiting for results, and nurses didn't ever know. 'Oh, I don't know what's going on. I think he's on the list, he's not on the list.'" Participants became frustrated and angry when they were unable to access information.

Sub-theme 3.2 - Being treated with compassion vs. being treated uncaringly. The human connection created between the care provider and the parent/family unit was at the core of *being treated with compassion.* Adult children described some nurses, physicians, and social workers as being guides and supports to them and their families, especially during times of transition to EOL care and through the parent's dying process. This sub-theme was characterized by the care provider being honest, attentive, and perceptive to parent and adult child needs. Participants were grateful when physicians showed compassion, listened, asked what was important, were honest and open when sharing information about the parent's illness, and involved families in the plan of care. Staff also conveyed compassion in the deep sensitivity shown, the little things nurses did, and through non-verbal communication, such as eye contact or a hug. *Being treated with compassion* meant that hospital staff cared about the parents and also their adult children.

Kate, who provided support to her mother as her father was ill and dying, described one physician's approach to conversations about end of life:

> *[My mom] finally felt that somebody listened to her and what was important to them for their care…So...Mom …right from the time she met [the doctor] had a real connection with her…For her even to say, you know, 'she gave me a hug;' Like that meant so much to her...[The doctor] talked to her, [and asked] 'what are your goals. What...do you want to see for him?'*

Cathy appreciated the attentiveness of the physician as her dad was dying in hospital, "My doctor, he'd come in and just say…'How's he doing' and, 'How are you?' It was just an acknowledgement."

Several participants commented very positively on the compassion, support, and guidance they received from nurses and social workers, especially during times of transition to EOL care and at the time of death. Participants were also moved by the way nurses kept dropping in and by the deep sensitivity shown by these care providers. Cathy recalled the way nurses spoke to her dying father, *"There was no... giving up on the humanity of it… 'This will make you feel better...Here, we'll move this pillow.'...It was really compassionate."* Gerald remembered:

> *"My goodness, was she ever [a] go getter...Lovely person. She'd come down and she'd say, "Oh, she shouldn't be in this room…goes away, and comes back in about a half hour and said, "We're moving her just around the corner to her own room, everything is cleared out, set up so you can have the privacy to be*

> *with your mom'…And anything you wanted…She was our advocate. She was just, just and surely special."*

In contrast, some adult children described a lack of compassion. *Being treated uncaringly* meant that doctors and nurses were cold, unhelpful, and demonstrating uncaring mannerisms. Two adult children perceived their parents received less attention when they were in rooms at the end of the hall or hidden behind curtains. Trish explained,

> *[S]he seemed to just be like, right out of their scope almost…she was down the other end of the hospital wing…and she's a very quiet woman, so there was not a lot of people came in and out. It's almost like, she was there, her meals came, but there was no other interaction with them.*

At times, participants interpreted a lack of compassion when staff delayed interactions, especially when there was uncertainty surrounding the parent's illness and the adult child was in need of support. Cathy recalls waiting in the emergency room as her dad lay delirious and screaming,

> *And [the doctor] said, 'I'll be in to see him later. There's no sense of me looking at him 'til I had the test back.' And I thought well, yeah, there is. Like it would help me to know the doctor has seen him. Like I understand – well,…he wasn't busy. That was the thing. Like, I was really annoyed, because I thought, "You're just standing here...Just come in the room, and say to me… 'Here's my name, I'm the doctor. We can't do anything right now, but we'll try to make him comf' -Like just comfort me a bit, 'cause I'm by myself ….Yeah, and the lack of compassion for me and my dad.*

Sometimes doctors conveyed insensitivity through the use of the phrase, “there is nothing more we can do for you” when sharing bad news. Trish remembered:

> *My mother-in-law…said that was repeated to her several times by the same doctor….Ya, we know it’s coming, and you’ve said there’s nothing more you can do. But, it’s like, what do you expect us to do with ‘there is nothing more you can do?’*

Other participants commented on nurse coldness. Being curt, abrupt, inattentive, or distancing communicated nurse coldness. Debra described the feeling of being distanced from nursing staff while visiting in the hospital, “So there’s an invisible line I wasn’t supposed to walk to.” Sometimes adult children described nurses as being very task oriented in caring for their parent and not taking the time to talk with family. Kate shared, “I don’t know that anybody said, ‘How are you doing?’” In the subtheme being treated uncaringly, no therapeutic relationship was developed between the staff and the adult child.

Sub –theme 3.3- Receiving optimal care and comfort vs. falling through the cracks. The subtheme *receiving optimal care and comfort* meant that adult children perceived that their parent received good physical care and was kept comfortable. Staff also extended comfort to adult children by providing cots and blankets as the children maintained vigil at the bedside. For most adult children, their parent’s comfort was the key priority, especially when they were transitioning to EOL care. Kelly emphasized, “Comfort is number 1…I would say just make them comfortable, especially if in your medical opinion, they’re not gonna be leaving the hospital anyway…you know, warm blankets, all that kind of stuff makes a huge difference.” Participants appreciated nurse’s attentiveness to their parent’s pain control needs. Rachel remarked, “If they heard him moaning, they were right in there giving him something to make him comfortable." Repositioning the parent, and maintaining hygiene was also important. Karen recalled, "They would come in every hour and move him from one side to the other side and, they kept him very comfortable. Very comfortable. They kept us comfortable."

Having a comfortable environment meant that there was sufficient personal space for the parent and family to spend valuable time together as family. Most advanced-age parents were in a private or semi-private room. Two participants talked about the change of environment after their parent had transferred to the second hospital and then received EOL care. "He was happy," Karen said. Rachel added, "And I think the atmosphere even changed." Karen recalled, "The kids were all allowed to come in…we spent the nights there." Being aware of their parent's prognosis and planning for EOL care within a caring environment also meant the adult children's stress level decreased.

Adult children also highly appreciated the amenities that were provided, such as a pullout bed, blankets, as well as open visiting hours. Gerald indicated, "The room was excellent, when they moved her to her own room, what more could you ask for?...They made a bed for my sister, they came, I mean how more thoughtful can you get than…?" Karen remarked, "They had a cart outside his room with coffee…cookies…Everything for us – everything there."

Even though many adult children understood how busy staff were on a medicine unit, adult children described situations in which they felt their parents were *falling through the cracks*. In contrast to receiving good physical care and a comfortable environment, some adult children described their parents as receiving poor physical care, such as being left unbathed, given poor mouth care, and meals that were not appropriate for their parent's swallowing ability. Participants were also upset with poorly maintained environments, such as commodes not being emptied, and bed sheets not being changed routinely. Some children also reported the coordination of care as an issue, especially in relation to patient transfers to another unit, room, or hospital.

Trish shared frustration in how she found her mother-in-law unbathed.

> *She was a woman who took very good care of herself...She dressed to the nines…So she knew and was very aware…I went in and saw her…that she hadn't even been bathed, her hair was sticky, and that was not my mother-in-law.*

Kate described the importance of good nursing care in reducing stress associated with her parent's illness. She also recalled the hurt and disappointment her well mother shared with her in association with the perceived sub-standard care provided to her dying father.

> *Just give them good care. So then I can...be with them and... my time with them isn't spent stressed and worrying about…why his mouth isn't done, why he's getting pressure sores because he's not being turned…My time should be about spending with him and seeing if he can remember things that might make him happy. And showing him pictures and doing stuff like that. Not…scrubbing his mouth out because it hasn't been done for a day or two.*

Some participants commented on the prolonged time that nurses took to answer call bells. Others commented on nurse lack of attentiveness. At least two adult children expected that nurses would check in to assess their parent every hour. When adult children perceived their parents were falling through the cracks, they reported needing to keep "a watchful eye" over care.

The subtheme *falling through the cracks* also extended to the plan of care. In one situation, there was confusion regarding medication when the parent was transferred to another ward, while in other situations there was confusion regarding goals of care and transfers to another facility. George said, “[The] staff [were] confused about the ICU drugs” when his parent was transferred to the medical unit. As a result, there was an interruption in the provision of pain medication.

Room or ward changes also negatively affected the parent’s continuity of care, and adult children were required to repeat their stories about their parent’s illness. Debra said, “But you’re also shifting rooms and places, and nurses, and information, and that’s when you just feel like…fall through the cracks.”

Two participants reported they were not informed about the room changes within the same hospital. They were shocked when they found the parent’s bed empty. Rachel shared her reaction, “Dead…can you imagine the shock of going there and – and your dad’s bed is made? Cause the only time you make a bed fresh is when somebody’s passed.”

Three participants reported challenges surrounding the transfer of care to another facility. Karen shared, “They called me one day and said they were gonna try to get him a room in [a hospital] for rehab…The next thing you know they’re shipping him to [another hospital]. Rachel added, “You’re sending him for rehab and…[now] there’s nothing that can be done for him? ‘Cause…we’re not expecting him to die. Like, we were not, at all.” Unclear goals of care and staff unawareness of prognosis contributed to the confusion.

Sub-theme 4.4 – Being treated with respect and dignity vs. being devalued as a person. Underlying all adult child - care provider interactions was the element of respect and dignity. *Being treated with respect and dignity* meant that adult children perceived that their parent was treated well as an individual throughout their parent’s final hospital stay. Respect was conveyed in how staff cared for and communicated with the parent. Providing a respectful death was also important. Candice commented on the respect nurses provided to her mother after being diagnosed with a stroke:

> *And one of the nurses…just said, ‘We don’t look…only at the diagnostics and the pictures.’ And she gestured with her hands…and turned her whole body towards my mom. And said, ‘We look at this,., and we judge what’s happening right here. And that’s how we…amend our care accordingly.’ You know? Which…spoke volumes to me…It’s … what I needed to hear.*

Nurses and physicians conveyed respect to adult children when they welcomed, and acknowledged the adult child’s role in assisting to develop the parent’s plan of care. Cathy said, “He sat down, he talked with me and listened to me. And that’s all I wanted from the other guy; was just like, acknowledge me.” Nurses also conveyed respect in the way they cared for the deceased parent and enabled family to spend time with their deceased parent. Karen said, “She…took his oxygen mask off and she folded his hands and she tried to make him look presentable for when we come in.”

In contrast, adult children described any perceived lack of respect as *being devalued as a person*. Adult children reported disrespect when they found their parent in disarray, unclothed, unbathed, or receiving meals that were inappropriate for their parent’s chewing ability. Four participants described a gap between their parent’s cognitive capabilities and the nursing care provided when their parent experienced cognitive changes related to delirium or dementia. One participant spoke about how hospital staff lacked skills in communicating with and caring for patients who have dementia. Kate commented:

> *And [mum] was absolutely horrified. The three [staff] went in, threw all of his covers off, took his gown off. Scrub, scrub, scrub, wiped him down, Left him*

> *totally exposed while they were doing it…But the dignity thing was …Like, would you treat a 40 year old post-op patient like that?*

Karen emphasized, “Treat them like you would want to be treated.” Rachel said, “As a human being, not as an old man or old woman.” They recalled their parent, who was normally cognitively intact, sitting in a specialized chair with an attached table, exposed and confused at a time when they were not yet aware of details surrounding the parent’s illness. Rachel indicated:

> *He just had this gown on. Half of it was like off, and he had a brief on, you could just see everything…I just think they just said, ‘Oh, he’s an old man...Who cares?’...They probably thought he should be in a nursing home. But he was – still had his wits about him and…I just think they did an awful thing to him.*

At times, participants also sensed that nurses, social workers, and physicians were disrespectful towards them as family members. Others described situations where they felt unacknowledged or devalued when suggestions they provided were disregarded by nurses or doctors. Debra recalled one staff member speaking to her in “really condescending” manner, while Kate remembered a staff member who “rolled his eyes” when she asked for a referral. Being disrespectful meant that care providers did not acknowledge adult children’s important role as their parents’ advocate.

Theme 4 - Reacting and remembering. This theme encompasses the emotional reactions and memories experienced of adult children, their evaluations of the quality of care received, as well as the sense of trust and confidence they had developed or lost because of the care received by their parent. When adult children perceived that their parent received high-quality care, they evaluated care as “super care” and “very respectful” (Rachel), “really exceptional" (Cathy), "terrific" (Karen), "amazing" (Debra), and "totally satisfied" (Gerald). Adult children shared comments such as "everything went perfectly. She was in no pain…the staff were great. And…she was, according to my beliefs, in heaven. What can be better?" (Dan), and "He got really good care" (Barbara).

Having an awareness of prognosis was an important factor influencing their reactions; therefore, the time surrounding the parent's transition to EOL care was often a critical moment in the hospital stay when all elements of high-quality EOL care merged and the hospital staff and family goals of care aligned so that everyone was "on the same page." Rachel recalled, "The atmosphere changed," with this meaning the stress and uncertainty that surrounded their parent's illness before had dissipated. Although this transition to EOL care varied in time from hours before the death to one week before the death, participants were highly appreciative of the care received during and after these transitions. Participants were also moved by the associated compassion shown by doctors and nurses. Debra recalled, "And [the doctor] was so compassionate…He was amazing."

High-quality care provided at the end of life enabled families to plan for EOL care and to spend quality time together. Often, lasting memories were created during these times. Dan recalls, "[I] sang ah, Amazing Grace to her as she was passing away. So that was very pleasant on my part." Cathy fondly remembered her parent's great-grandchildren playing on the hospital floor and the five year old, "made a song for him" and "sang him the song…It was as good as it gets." Participants also recalled the quality of death as "very peaceful" (Danielle). High-quality EOL care contributed to an increased confidence and trust in the health care system; Rachel said, "you could go …down for a coffee, knowing that your dad was being well looked after." In essence, high-quality care at the end of life contributed to a good death; one that encompassed comfort, dignity, peacefulness, preparation, and quality family time.

In contrast, poor quality care at the end of life created feelings of “hurt, anger, and disappointment” (Kate). Adult children described feeling “really annoyed” (Cathy) or sensing a “lack of compassion” (Cathy) from health care providers, and they expressed a lack of support when their role was not acknowledged or when staff did not involve them in the care planning process. Karen described feeling “robbed” with regards to not being given the opportunity to arrange a home death. Sometimes participants were left with negative images. Rachel said, “Cause in – in your mind, I’m thinking…you shouldn’t have to picture your dad in a Geri-chair, exposed to everybody – like, that’s not a memory that you wanna take about your dad.” Some participants experienced a loss of trust in the health care system. Debra indicated, “I didn’t realize how much fear I had, you know…and lack of trust.”

Three adult children reported that having a positive personality and faith influenced how they coped with the situation. Trish commented, “I’m a person that deals with things head on,” while Cathy said, “Well, here’s what you have to do, so you do it.” Dan reported his Christian faith helped him perceive the situation with hope and positivity, “My belief in life afterwards plays a big part in how I perceive this.”

Substantive Theory of High-Quality Care at the End of Life for Advanced-age Adults

Through the qualitative interviews with adult children, which followed the establishment through the DAD analysis that advanced-age adults comprise a substantial proportion of hospital decedents in Ontario, a substantive theory of high-quality care at the end of life for advanced-age adults was developed. This substantive theory is represented in Figure 1 and is summarized in the following section.

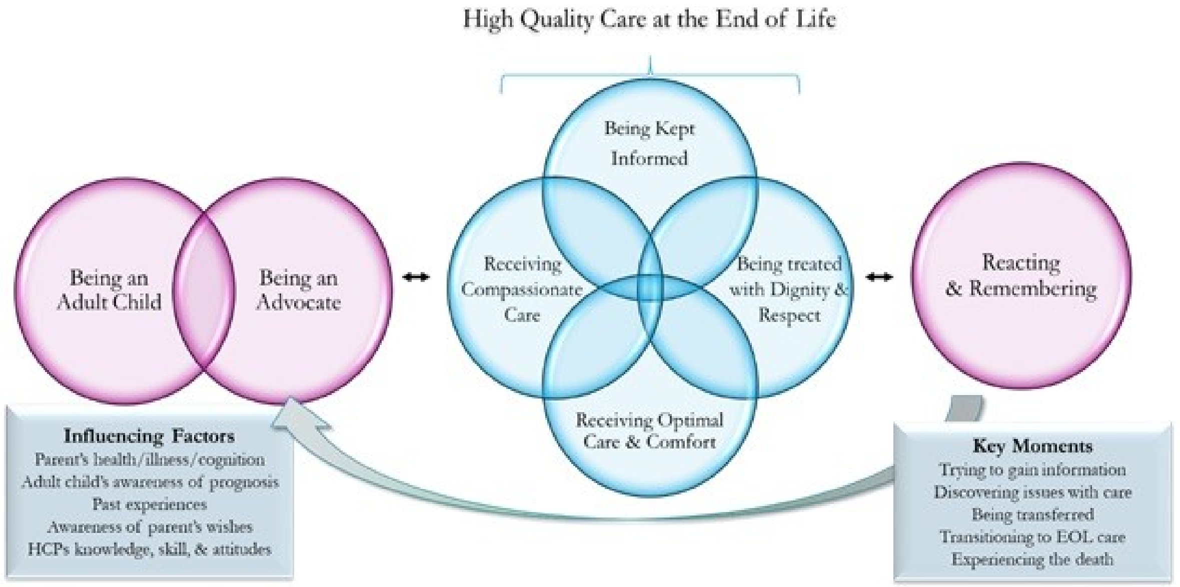


Figure 1. Substantive theory of high-quality care at the end of life for advanced-age adults

The substantive theory of high-quality care at the end of life for advanced-age adults consists of the four described themes; (a) *being an adult child,* (b) *being an advocate,* (c) *receiving high (or low) quality care at the end of life, and* (d) *reacting and remembering*.

The theme *being an adult child* is characterized by the concern and sense of responsibility that adult children have for their parent. The care of focus depends on the adult child's awareness of the closeness of their parent's end of life. The adult child's sense of responsibility and their values and expectations regarding quality care are at the core of what motivates their advocating behavior.

The theme *being an advocate* encompasses the activities adult children engage in to ensure their parent receives the quality of care that they need. Advocating behaviours include searching for information to understand their parent's illness, asking doctors and nurses questions about the care, and asking staff to carry out nursing care such as bathing, repositioning, mouth care, and suctioning. To advocate effectively, adult children also require support, reassurance, and acknowledgement as they carry out their role.

As adult children advocate for best care, they encounter facilitators and barriers to receiving high-quality care at the end of life. High-quality care consisted of being kept informed, receiving care with compassion, receiving optimal care and comfort, and being treated with respect and dignity. In contrast, low-quality EOL care consisted of being left in the dark, being treated uncaringly, falling through the cracks, and being devalued as a person.

The theme *reacting and remembering* is characterized by the reactions and memories created because of the care given. When adult children perceived that their parent received high-quality of care at the end of life, they communicated appreciation for the care received, rated the quality of care higher, and indicated trust and confidence in the health care system. They also remembered aspects of their parent's death as being comfortable and peaceful. When they perceived a low quality of EOL care, adult children remembered anger, disappointment, and hurt. They rated the quality of care poor, and communicated mistrust in the healthcare system.

As also illustrated in the substantive theory, several factors influenced adult children's perceptions of the quality of care received by their parents at the end of life. These factors included awareness of the parent's prognosis, the parent's past illnesses, adult children's past experiences of working in health care and having other loved ones die in palliative care unit, and the perceived attitudes, knowledge, and skills of hospital staff. Adult children were better able to make decisions for their parent when they understood their parent's illness and were aware of the prognosis. Having an awareness of what their parent's previously expressed care wishes were was also helpful. The parent's health and illness influenced adult children's expectations of the illness course; the greater the uncertainty associated with the illness, the greater the stress experienced by the adult child. The adult child reflected upon their past experiences and compared these to the care their parent was receiving. When adult children had previous exposure to palliative care services or had a healthcare background, they often had higher expectations of care for their parent. Perceived health care provider attitudes, knowledge, and skills also influenced perceptions of care. Adult children identified empathy, compassion, communication skills, and good nursing skills (providing personal care and comfort) positively; in contrast, staff who did not have these skills were viewed as being cold and uncaring.

The consequences of receiving high-quality care at the end of life were numerous. Adult children had an increased awareness of the parent's illness and prognosis, and were better able to make care decisions for their parent and plan for the end of life when they were kept informed. They felt supported and reassured when information was delivered with compassion and respect. When their parent also received optimal physical care, they were reassured that their parent was treated well as an individual and kept comfortable. When EOL care transitions were successful, adult children remembered poignant moments associated with the death surround. In summary, high-quality care at the end of life contributed to a good death; one that encompassed comfort, dignity, peacefulness, preparation, and quality family time.

Chapter Summary

This chapter presented the findings of the quantitative and qualitative phases of this sequential mixed methods study. The quantitative phase described advanced-age adults who died in an Ontario acute care hospital and the care they received in their final hospital stay ending in death; with an analysis of CIHI Ontario DAD for the fiscal year, 2014-2015 highlighting the demographic and health-related characteristics of advanced-age decedents, as well as their hospital use characteristics. As indicated above, advanced-age adults (aged 85+) accounted for

32.7% (n = 13,450) of all hospitals deaths, with the majority (82.1%) dying on a medicine (non-surgical) and palliative care services. The majority of advanced-age decedents (64.1%) were admitted from home. Overall, the median LOS in hospital for advanced-age decedents was only 6.0 days and life-sustaining interventions were used infrequently. Only 12% of advanced-age adults died in SCUs.

The qualitative phase aimed to capture adult children's perceptions of the quality of EOL care received by their advanced-age parent who died during a non-surgical admission in an Ontario acute care hospital. The chapter presented findings from interviews with 15 adult children regarding the quality of care received by their 12 advanced-age parent during their parent's final hospital stay ending in death. Four themes were presented and a substantive theory for high-quality EOL hospital care for advanced-age adults was developed.

CHAPTER FIVE

DISCUSSION OF FINDINGS

This sequential mixed methods study aimed to develop a substantive theory of high-quality EOL hospital care for dying non-surgical patients who were aged 85 and older largely based on the perceptions of their adult children, but also through CIHI hospital data. The main purpose of using mixed methods is to develop a greater understanding of the research topic than either the quantitative or qualitative phase could do alone (Creswell & Plano Clark, 2011; Leech & Onwuegbuzie, 2009). This chapter presents a review and discussion of key findings from the quantitative and qualitative phases of this study. An integration of both phases is also discussed.

Discussion of Quantitative Findings

Based on the analysis of the CIHI DAD for Ontario, the quantitative phase of this study revealed several key findings on the socio-demographic and health related characteristics of hospitalized advanced-age decedents, their hospital use in general, and their use of life-sustaining therapies during their final hospital stay. This study demonstrated that around one-third of hospital decedents in Ontario were aged 85+, most of whom received medical care services, and few were known to have a palliative plan prior to hospital admission. Yet, few advanced-age decedents received life-sustaining treatment which could indicate either ageism or patient/family choice. This study phase also showed nursing care was the main service provided in hospital, raising the question of whether more home care supports would be able to prevent the crises that send older people to the ER before being admitted and dying in hospital. Regardless, as older people are dying in hospital, and some always will, quality EOL care is needed.

Socio-demographic and Health-Related Characteristics of Advanced-age Decedents

This study demonstrated that quality EOL care is needed in all acute care hospitals as hospitals are obviously one location where death can and does occur. Advanced-age decedents accounted for 32.7% of all hospital deaths that occurred in Ontario during in the year 2014–2015. In addition, when compared to all Ontario decedent deaths (aged 85+) for the same year (Statistics Canada, 2017a), acute care hospitals were the location of death for 38.7% of all advanced-age adults in Ontario. In comparison to this study's findings, higher percentages of advanced-age adults died in hospitals (41.0% – 61.8%) in Manitoba, the UK, and England (Fleming et al., 2010; Hunt et al., 2014b; Menec et al., 2007), and a similar proportion of advanced-age adults (33.5%) died in Belgium hospitals (Houttekier et al., 2013). Furthermore, this study demonstrated that small community and larger teaching hospitals have an important role in supporting dying advanced-age adults and their families, as the largest proportions of decedents died in these locations (47.4% and 24.1% respectively). Access to specialty palliative care services in these and other locations is essential to ensure optimal EOL care is available for those needing this level of specialist support.

This quantitative study phase found advanced-age adults died mainly of non-cancer diseases. Hospitalized advanced-age decedents often had primary diagnoses such as diseases of the circulatory system, diseases of the respiratory system, and certain infections and parasitic diseases. Primary diagnoses related to neoplasms were far less common. These findings are consistent with other studies that found infection, pneumonia, and organ failure more common than cancer diagnoses (CIHI, 2007, 2011, 2014a; Esteve et al., 2009; Gardiner et al., 2013; Seah et al., 2005; Somogyi-Zalud et al., 2002; Twomey et al., 2007; Verhofstede et al., 2017). The high prevalence of non-cancer diagnoses in this study emphasizes the need for a growth in non-cancer related palliative care services in hospital and increased skills of all clinicians to care for these individuals. To that end, it is helpful that research is now increasingly being conducted on non-cancer terminal populations, such as those living with advanced congestive heart failure, Parkinson's disease, and end-stage renal disease (Boersma et al., 2017; McIlvennan & Allen, 2016; Moss, 2016).

Discussion of Palliative Care Diagnoses in Advanced-age Hospital Decedents

This study found that approaching death is not always easily recognized in the advanced-age population, as few people were known to have a terminal illness prior to coming to hospital. While this study offers new information about palliative care diagnoses in dying hospitalized advanced-age adults in Ontario, the findings are comparable to research conducted by CIHI (2011) who examined the EOL care provided to hospital decedents aged 19+ in the Atlantic provinces of Canada. This study found that a lower proportion of advanced-age decedents had a MRDx of palliative care as compared to hospital decedents aged 19+ in the CIHI (2011) study (21.2% vs. 29.8%). In contrast, this study found a slightly higher proportion of advanced-age decedents with palliative care diagnoses in any diagnostic code as compared to the CIHI (2011) study (62.8% vs. 59.4%). While some decedents may have received treatment for reversible conditions associated with a palliative diagnosis, these findings show it takes time to determine that someone in hospital is irrevocably dying, and that care should then become primarily palliative or comfort-oriented in nature. The low percentage of decedents identified as palliative in both studies also demonstrates a need to ensure that education and systems are in place to assist clinicians to recognize approaching death earlier and not fear talking about it with the family or the patients. Enhanced collaboration between community and hospital sectors must also occur to ensure that existing palliative care plans are communicated during transitions in care locations.

Discussion of Hospital Utilization by Advanced-age Decedents

This study found that the vast majority of advanced-age decedents were admitted through the ER (91.3%), they received care mostly through medicine (non-surgical) services (69.5%), and their median LOS was quite short (6.0 days, mean 12.3 ± 21.8). These findings could indicate that advanced-age adults are coming into hospital during crisis situations and dying relatively quickly. While the LOS was found to be comparable to other studies (mean 9.6 days – median 18 days) (Afzal et al., 2009; Hesse, 1995), this study's finding of the high use of the ER among advanced-age decedents is both revealing and concerning.

This study found that a higher proportion of advanced-age decedents entered the hospital through the ER as compared to decedents of all ages in Canada (except Quebec) as found in Wilson et al.'s (2017) study (91.3% vs. 79.0%). While ER use may be very appropriate, a high rate of ER use is a general indicator of poor quality EOL care (Cancer Quality Council of Ontario, 2016; Local Health Integration Networks & Quality Hospice Palliative Care Coalition of Ontario, 2011). However, the majority of advanced-age decedents were also not recognized (or coded) as having a palliative plan prior to hospitalization. This lack of palliative plan may indicate advanced-age decedents had an unexpected decline in health. The high percentage of ER use may also indicate that, although aging and dying in place is a provincial goal (Government of Ontario, 2017), the services designed to promote this goal may not be enough to prevent the ill health crises that result in ER visits and hospital admissions. As found in Reyneirs et al.'s (2016) study, an ER visit may have been precipitated by an acute situation that the local care community was unable to manage. Family physicians participating in Reyneirs et al.'s (2016) study reported that 85% of EOL hospital admissions to geriatric wards in Belgium were related to inadequate supports in the decedents' previous care settings. Alternatively, patients and/or their families may have preferred admission to hospital because they felt safer in hospital or believed the hospital could deliver better care (Reyneirs et al., 2016). Further research is required to better characterize the needs of advanced-age decedents coming to ERs. Moreover, the high use of ER and medicine services indicate that these places are prime locations to initiate quality improvement projects; projects that are designed to identify patients in need of palliative care, initiate goals of care discussions, and initiate care planning based on the patient's and family's needs and preferences.

Discussion of Life-sustaining Treatment in Hospital

This study found that few advanced-age decedents received life-sustaining treatments such as CPR, mechanical ventilation, chemotherapy, and dialysis. Ontario advanced-age decedents thus underwent less CPR (3.2%) as compared to the rate identified in other earlier non-Canadian studies (3.6% - 24.0%) (Ahronhein et al., 1996; Formiga et al., 2007; Hesse, 1995; Somogyi-Zalud et al., 2002; Steindal et al., 2013). The low use of life-sustaining treatment could indicate that Ontario hospitalized advanced-age decedents now are choosing less curative or life-sustaining oriented treatments than they did previously. However, the low percentage of treatments being offered may also be related to ageism. As an example, studies have shown that patients who were designated as DNR in hospital received fewer life-sustaining treatments as compared to patients who wanted CPR (Fuchs et al., 2017). This difference was thought to be influenced by the clinician's perception of patient characteristics (Fuchs et al., 2017). Although treatments such as CPR are less common in advanced-age adults, clinicians must be cautioned against using the patient's chronological age as the primary decision-making criterion when discussing treatment options with advanced-age adults and their families (Cook et al., 2017).

The most common life-sustaining treatment that Ontario advanced-age decedents received in 2014-2015 as captured by the CIHI DAD was blood transfusions (15.4%), with Somogyi-Zalud et al. (2002) and Hesse (1995) both finding a similar use of blood transfusions in dying advanced-age people in their studies. Blood transfusions may be appropriate care in hospital for very-old people, however, as anemia is a common health issue for advanced-age adults (Beyer et al., 2010). As such, blood transfusions may be appropriately given early in a hospitalization to attempt to revive the person and prevent a dying trajectory. Blood transfusions likely occur more often than other life-supporting interventions as they are considered a low cost and low-intensity intervention (Hesse, 1995).

This study found that a much lower proportion of advanced-age decedents in Ontario were admitted to SCUs as compared to Somogi-Zalud et al.'s (2002) US study of decedents aged 80+ (21.2% vs. 54.0%). Somogyi-Zalad et al.'s (2002) study occurred in four large teaching hospitals. As indicated by Heyland et al. (2000b) and Verhofstede et al. (2017), higher SCU use may be related to being cared for in a larger hospital and thus the availability of SCU beds. Consistent with other studies (Hesse, 1995; Steindal et al., 2013), this study found that 12.0% of advanced-age decedents died in SCUs. Hesse (1995) found that similar proportions (12% – 15%) of very-old people dying in SCUs, while Steindal et al. (2013) found 10.1% of very-old people died in SCUs.

It is also important to note that the number of advanced-age decedents who died in SCUs represented only 4.6% of all advanced-age decedents who died in Ontario hospitals that year. One explanation for such a low proportion of very old people dying in SCUs is that more Canadians are living to advanced old age now because they are healthier and so dying now will more often occur after a sudden decline in health for people living with advanced-age senescence

(Tanuseputro et al., 2015). For example, in this study, Ontario advanced-age decedents who died in a SCU had a median of 3.0 LOS days, indicating an abrupt dying process and also possibly an abrupt onset of an acute illness that made SCU care seem appropriate. Alternatively, advanced-age adults may be increasingly choosing to undergo life-sustaining treatments and thus indicate that they do not want aggressive EOL care (Fleming et al., 2016). Research is needed to gain a greater understanding of why advanced-age adults die in SCUs or other hospital locations.

Mixed Method Integration

Integrating the results of the quantitative and qualitative findings of this mixed methods study demonstrated several complementary patterns. First, the evidence reinforces that dying often comes unexpectedly in the advanced-age population. Thus the element of unpredictability of death was evident in both phases. In the quantitative phase of the study, a very high percentage of advanced-age decedents entered the hospital through the ER, only 1 out of 5 decedents had a MRDx of palliative care, and a very small fraction of these were known to have a palliative care plan prior to hospitalization. This pattern would suggest that admission to hospital is often precipitated by a crisis situation, with this concern supported by findings gained in the qualitative phase. In the qualitative phase, the reasons parents were admitted to hospital were quite legitimate. Many parents required treatment for health issues such as severe infections, pneumonia, and cardiac problems. Only one parent was known to be dying and was hospitalized because of a need for better pain control.

However, an element of surprise was made evident in the qualitative phase. The majority of children (11/13) were surprised over the possibility of the death of their parent during what became the final hospital stay. The low percentage of advanced-age decedents with a MRDx of palliative care and the element of surprise experienced by adult children may be related to the unpredictability of deaths associated with old-age frailty and organ failure disease trajectories. Consistent with another study (Hawker et al., 2006), many adult children in this study commented that their parents had suffered from similar acute illnesses in the past (e.g. infections), and were treated and recovered. Many expected that their parent would again recover after the treatment of what they believed to be a reversible illness, during what instead became their final hospital stay. The findings of this study reinforce the challenges of diagnosing dying, particularly when the dying person is at an advanced age (Gardiner et al., 2013). Research should be undertaken now, in light of population aging and the findings of this study that showed roughly 1/3 of all hospital patients who died were very advanced in age, to ensure dying advanced-age adults are recognized as dying in a timely fashion to ensure they receive the EOL care needed.

The element of surprise was also in contrast with adult children's awareness of their parent's previously stated wishes for DNR and also their parents often deteriorated health condition. This element of surprise has been identified in other studies of bereaved caregivers (Donnelly & Battley, 2010; Dose et al., 2015; Hawker et al., 2006; Jacobs et al., 2002; Odgers et al., 2018), and this surprise resembles Cable-Williams' (2011) insight regarding the difference between general awareness and clinical awareness of dying. In Cable-Williams' (2011) ethnographic study, clinicians working in LTC facilities were quite aware that most residents were very old and would someday die (general awareness); however, the recognition of imminent dying (clinical awareness) did not occur until just a few days before death. Many adult children in this study responded in the same manner; they knew that death was possible sometime in the future, but most did not expect death to occur during the final hospital stay.

Integrating results from both phases of this study also indicated that advanced-age decedents required substantially more nursing care than families were able to provide at home. This study found relatively high percentages of ALC days among all hospitalized advanced-age decedents in Ontario as well as the subset receiving medicine services (22.6% and 26.1% respectively). Usually patients are designated ALC when they no longer require the intensity of services required in an acute care setting (CIHI, n.d.) and when they are waiting for care to be made available in other places. In the qualitative phase, 75% of adult children indicated that their parent required significant assistance with personal care in the two weeks prior to hospital admission. Family resources were also limited; 75% of parents were widowed and 53.3% of adult children were still working. However, two participants indicated that they would have supported a home death had they known their parent was dying. These results reinforce the need for clinicians to inquire about family resources and ask the patient and family about their preferred location of death as early as possible in the care-planning process and as soon as death is recognized as approaching. In so doing, clinicians can help enable the most optimal death location and perhaps also the most optimal dying process for both the dying person and what will become their bereaved family member(s).

The increased need for nursing services and the lack of family capacity to provide this care, as identified for many of the interviewed adult children, creates a situation in which families are reliant on hospital staff to care for their dying advanced-age parent. As such, adult children would have or would gain certain expectations about the quality of EOL care that their parent should receive. As identified in the qualitative phase, adult children reported experiencing a strong sense of responsibility to ensure their parent receives the care they need. Depending on the quality of EOL care received, adult children are placed in a situation of advocacy and concern. Together, the level of unpredictability and surprise evident in both phases of the study, and the increased need for hospital staff to care for their dying advanced-age parent speaks to the need for clinicians to recognize when patients are dying to ensure they are able to provide families with timely information, adequate support, and choices about goals of care.

Discussion of Qualitative Findings

The qualitative phase of this study identified four themes relating to quality EOL hospital care for advanced-age adults; (a) being an adult child, (b) being an advocate, (c) receiving high (or low) quality EOL care, and (d) reacting and remembering. It was evident that adult children carried a strong sense of responsibility and acted as advocates to try to ensure their parent received the type and quality of care that their parent required. In several cases, their advocacy was limited by the low quality of information received regarding their parent's final hospitalization and also their lack of awareness of the closeness of death.

A moral sense of duty or filial responsibility to care for older parents was identified by adult children in Guberman et al.'s (2006, 2012) study, as well as by bereaved caregivers in other studies (Cohen, Auslander, & Chen, 2010; Cohen, Auslander, Dror, & Breuer, 2016; Donnelly & Battley, 2010; James et al., 2009). In this study, adult children also had a keen sense of protectiveness toward their dying parent and were motivated to advocate for what they believed to be the right care. This orientation is similar to other studies (Donnelly & Battley, 2010; James et al., 2009). James et al. (2009) found families were watchful and protective acting "purposefully so that their loved one would get optimal treatment" (p. 261).

This sense of caregiving and protectionism that adult children had for their older parents is similar to that of parents caring for seriously-ill children (Bell & Richard, 2000; Loopstra, Strodl, & Herd, 2015). Theories associated with parenting could therefore be used to further explore the concepts of responsibility and advocacy that adult children experience when reciprocally caring for a dying parent (Carpenter, 2001; Karantzas, Evans, & Foddy, 2010). For example, Bell and Richard (2000) presented a theory proposing that the essence of caregiving lies in the bonds between the caregiver and dependent. The emotion of caring generates the motivation to provide caregiving while the empathetic perception of another's welfare, combined with a sense of responsibility (defined as a calling forth and commitment to ensure another's wellbeing), drives caregiving behaviour toward the set goal of meeting another's need (Bell & Richard, 2000). Rather than caregiving being based on family obligation, adult children were more simply motivated by their desire to ensure their parent's needs were met. As also identified by Stajduhar et al. (2011), further research on the concept of responsibility is needed. The research knowledge generated could help clinicians to understand and anticipate adult children's needs as they care for their dying advanced-age parent.

This study also identified four sub-themes associated with high-quality EOL care; (a) being kept informed, (b) receiving compassionate care, (c) being treated with dignity and respect, and (d) receiving optimal care and comfort. These sub-themes are similar to other domains identified for high-quality EOL care (see Heyland et al., 2006; Howell & Brazil, 2005; Nelson et al., 2010; National Consensus Project for Quality Palliative Care [NCP], 2013; Stajduhar et al., 2011; Steinhauser et al., 2015). The sub-themes also reflect current priorities in the provision of quality EOL care (CHPCA, 2015; LACDP, 2014; Local Health Integration Networks & Quality Hospice Palliative Care Coalition of Ontario, 2011; Marie Curie, 2017; NCP, 2013; Ministry of Health and Long-Term Care, 2016b).

The need to be kept informed about the condition of a dying loved one was a common theme found in many studies (Donnelly & Battley, 2010; Jacobs et al., 2002; Odgers et al., 2018;

Stajduhar et al., 2011; Steinhauser et al., 2015). In this study, adult children were kept informed when given timely information regarding their loved one's illnesses, prognosis, and limitations of life-sustaining treatment. Being kept informed and receiving regular updates enabled children to understand the gravity of their parent's illness, increase their awareness of their parents approaching death, and better engage in the decision-making processes regarding EOL care. Several adult children described successful transitions to EOL care as key moments in the hospital EOL care experience. Unfortunately, as in Jacobs et al.'s (2002) study, the adult children in this study often reported struggling to gain sufficient information regarding their parent's illness, thus limiting their ability to participate actively in ensuring quality EOL care for their loved one.

Communication and decision-making regarding EOL care are high priorities for quality improvement in EOL care (Heyland et al., 2010a). Hospitals should implement systems to ensure that timely goals of care discussions occur with patients and family members. The importance of goals of care discussions is highlighted by the number of articles published on this topic (Adams, Bailey, Anderson, & Docherty, 2011; The Gold Standards Framework, 2011; Kirkpatrick, 2015; Roze des Ordons, Sharma, Heyland, & You, 2015; You et al., 2015; You, Fowler, & Heyland, 2014). Several authors have presented helpful strategies to help clinicians with such conversations (Roze des Ordons et al., 2015; You, Fowler, & Heyland, 2014).

Unfortunately, this study found the timing of when adult children became aware of their parent's impending death varied greatly. Clinicians play a vital role in informing families of their loved one's changing health status. To assist clinicians in their role, hospitals could implement tools and processes to also enhance clinician recognition of an impending end of life such as the Gold Standards Framework or a functional assessment tool such as the Palliative Performance

Scale (Oladjide et al., 2007; The Gold Standards Framework, 2011; Weissman & Meier, 2011). The Gold Standards Framework (2011) lists triggers that signal a person’s approaching end of life. One trigger is the surprise question “Would you be surprised if this patient were to die in the next few months, weeks, days?” (The Gold’s Standard Framework, 2011, p. 1). The Palliative Performance Scale (PPS) has been validated and used to predict mortality in both cancer and non-cancer palliative patients in a tertiary acute care center (Oladjide et al., 2007), and it is used in palliative care units, LTC facilities, and in home care to assess and communicate changes in a person’s functional status and signal the need to adjust the plan of care (Gill, Hillier, Crandall, & Johnston, 2007).

In this study, adult children appreciated when their parent received optimal care and comfort, a finding similar to other studies (Heyland et al., 2006; James et al., 2009; Nelson et al., 2010; Stajduhar et al., 2011; Steinhauser et al., 2015). This sub-theme resembles the “tangible features” associated with quality EOL care that Stajduhar et al. (2011, p. 264) described. Tangible features were described as “what is (and is not) done,” such as the provision of personal care, pain management, and emotional support (Stajduhar, 2011, p. 264). In this study, adult children also described optimal care as good nursing care (i.e. hygiene, mouth care, repositioning, and mobilization of the patient when appropriate). Additionally, having a coordinated plan of care in place and continuity of care was important. This information is not surprising. In Heyland et al.’s (2006) study, family members rated the relief of physical symptoms among the top five elements important in EOL care. Receiving good care when the family was not able to be present was also identified as a priority area for improvement (Heyland et al., 2010a).

This Ontario hospital study also adds to the evidence base regarding the concept of compassion in EOL care that was created by Sinclair et al. (2016). As in other studies of bereaved relatives, clinicians conveyed compassion to the parent and adult child through warmth, attentiveness, and responsiveness to their parent's and family's needs (Donnelly & Battley, 2010; Sinclair et al., 2016; Stajduhar et al., 2011). A therapeutic relationship was fostered with adult children when the clinician established a connection with them, and took the time to listen and ask what was important to them. Adult children appreciated the respect shown toward their parent and themselves, with this also shown in other studies of bereaved caregivers (Bussman et al., 2015; Donnelly & Battley, 2010; Odger et al., 2018; Nelson et al., 2010; Stajduhar et al., 2011). Important aspects of high-quality EOL care in this study also included valuing family input, providing support to the family, and offering an environment conducive to family privacy.

In this study, adult children were protective of the dignity and personhood of their advanced-age parent. Having their loved ones treated humanely and as a person rather than a number was also important to caregivers in Bussman et al.'s (2015) study. In this study, several children reacted negatively when they perceived that their parent was being treated as a "child" or as an "old" man or woman. This issue often occurred when their parent experienced delirium or had dementia. Some adult children thought that doctors and nurses did not take the time to understand the patient's baseline cognitive level. The adult child's need for clinicians to recognize their parent's personhood spoke to Steinhauser et al.'s (2015) concept of "affirmation of the whole person" (p. 949). Bereaved family caregivers in Steinhauser et al.'s (2015) study, wanted clinicians to know their dying relative as a person and so beyond the disease status and to care for their relative with dignity.

Consistent with other studies, this study identified important outcomes associated with high-quality EOL care (Heyland et al., 2006; Stajduhar et al., 2011; Steinhauser et al., 2015). These outcomes were satisfaction with care, trust and confidence in the health care system, and remembering poignant moments associated with spending time with the dying parent. Similar to the "personal and affective features" identified by Stajduhar et al. (2011, p. 266), this study identified that when adult children met facilitators that helped them ensure the parent had good care, the children were appreciative; but when barriers were encountered, the adult children felt anger and frustration. In this study, satisfaction with care was rated lower when adult children encountered barriers. This study thus provides evidence regarding factors associated with "good" and "bad" deaths. As identified in a literature review, there is higher potential for a bad death to occur when there are uncontrolled symptoms, the death is unexpected, or when the dying person receives undignified care (Wilson & Hewitt, 2017).

Additionally, the valuable time adult children spent with their dying parent in hospital contributed to a sense of "completion" as described by Steinhauser et al. (2015). Many adult children shared touching memories associated with the quality EOL care provided; the song that was sang to Great Grandpa as he was dying, the birthday party held for a mother-in-law, and a son who sang Amazing Grace as his mother was dying. To ensure positive outcomes for the survivors, continued improvement in the provision of high-quality EOL care is needed. Dame Cicely Saunders once said, "How people die remains in the memories of those who live on" (as cited in Meyer, 2000, p. 377).

Several relationships between the four qualitative themes were evident in this mixed methods study. First, adult children presented a continuum of advocating behaviours. For example, uncertainty about their parent's illness combined with lack of information from health care providers served to increase the adult child's advocating behavior of searching for information. In turn, the lack of communication also served to decrease the children's sense of trust with the health care team and increase negative reactions. In contrast, when presented with high-quality information and EOL care, adult children were less inclined to search for information. They also presented greater trust in the health care system and responded more positively.

This mixed methods study also demonstrated that past death experiences influenced one's expectations and evaluations of quality EOL care in the present. Adult children frequently compared past death experiences with the care that their parent had received. For example, having a good palliative care experience in the past resulted in greater expectations for EOL care in the present. When children encountered barriers obtaining the expected type or level of EOL care, they became frustrated and angry. In Canada and abroad, there is recognition that the delivery of the best possible care should occur throughout the natural progression of a chronic disease (ANZSPM, 2014; Chasen & Dosani, 2015; CHPCA, 2015). This study supports that high-quality EOL care for advanced-age adults includes the following elements:

- Recognition of the possibility of approaching EOL.
- Timely and sensitive communication with the advanced-age parent and their family regarding the dying person's illness, prognosis, and options for care with those identified as important to dying person.
- Supported decision-making in accordance to the needs and wishes of the dying person, including routine review of goals of care.
- Optimal care and comfort to the dying person, including
    - A coordinated plan of care,

  - Personal care, symptom management, and psychosocial/spiritual support that is responsive to patient needs,
  - Care that is given with compassion, respect, preservation of dignity and personhood (avoiding ageism),
  - Care in a clean, comfortable environment, and
  - Continuity of care.
- Optimal care and comfort to family, including
  - Recognition and support of the family,
  - Valuing and engaging family input,
  - Providing sensitive and responsive care with compassion and respect, and
  - Creating a comfortable environment that is conducive to family visiting.

This study also highlighted the need for a systems approach to help clinicians recognize cues that indicate advanced-age adults are approaching the end of life, and to initiate timely goals of care discussions. Adult children identified that being kept informed was a key domain associated with high-quality EOL care. Families require timely, open, and honest communication regarding their loved one's illness so that they can advocate for care that is consistent with their loved one's values, goals, and preferences (CHPCA, 2015).

Hospitals can adapt systems of care that would incorporate structures and processes to enable staff to provide the right care at the right time. These may include implementing EOL care guidelines designed specifically for hospitals, patient and family assessment tools, tools to assist in the EOL decision-making process, staff education programs, and patient/family education pamphlets on topics such as EOL decision-making and stages of dying. When integrated as part of hospital care, such quality improvement projects have showed positive results (Verhofstede et al., 2016).

This study demonstrated that hospital staff education regarding delirium and dementia is an area in need of improvement. Education about the assessment of changes in cognition, and the prevention and treatment of delirium is needed. Education regarding the management of challenging behaviours related to delirium and dementia is also important; when managed poorly, adult children reported feeling upset and angry.

Despite the barriers that can impede the provision of high-quality EOL care in the usual fast-paced environment of the hospital, nurses are strongly committed to assisting patients in achieving a good death and report feeling deeply rewarded to have shared in the EOL experience with patients and their families (Gagnon & Duggleby, 2014). This study presented a substantive theory for high-quality EOL care for advanced-age adults, one highly relevant as 1/3 hospital decedents are advanced in age, and this figure could rise as population aging continues. Nurses can use the theory to conduct patient/family assessments, influence actions consistent with high-quality EOL care, evaluate outcomes associated with quality EOL care, and guide nursing education.

Appendix H (Receiving high-quality of care at the end of life – Helpful tips for clinicians) lists behaviours identified by adult children as being important to their parent's care. For example, clinicians provide quality EOL care to advanced-age adults and their families by ensuring they provide timely and sensitive information from the time the parent arrives in the emergency room and throughout the hospital stay. Nurses can act as guides and supports as families navigate the unfamiliar territory associated with their parent's approaching end of life. By routinely checking the patient's progress during hourly comfort rounds, nurses can remain sensitive and responsive to patient and family needs. The substantive theory highlights the need to recognize the parent's previous cognitive baseline and abilities. This study thus highlights the need to ensure clinicians promote respect and ensure privacy for the parent while also avoiding ageist attitudes. Appendix H also outlines important ways of meeting the patient's personal care and comfort needs.

The substantive theory emphasizes the importance of noting key moments when increased needs may arise. Key moments occur during times of uncertainty, for example, at the beginning of the hospital stay when families tend to have difficulty gaining information, during transitions from curative to EOL care, and the time surrounding the death. Appendix H also lists important consequences or outcomes of high-quality EOL care for advanced-age adults.

Quality improvement initiatives should also incorporate evaluation measures reflecting these outcomes such as death occurring in the patient/families preferred location, and documentation of goals of care discussions and patient/family treatment preferences (Bainbridge & Seow, 2016; Dy et al., 2015). Existing quantitative measures of family experience or satisfaction, such as the CANHELP tool (Heyland et al., 2010b; Heyland, Jiang et al., 2013), the Toolkit After-Death Bereaved Family Member Interview (Teno, Clarridge, Casey, Edgeman-Levitan, & Fowler, 2001), or the CaregiverVoice survey (Seow et al., 2016; Seow et al., 2017) could be reviewed to ensure inclusion of high-quality of care elements that are unique to the care of dying advanced-age adults.

Study Limitations and Strengths

This study had four limitations and a number of strengths. The first limitation is that this study examined the characteristics of advanced-age decedents aged 85 and over, and so did not examine decedents of younger age groups. Therefore, the CIHI DAD results presented in this study may not be generalized to other age groups or to any other country. The second limitation is that the CIHI DAD only contains a select number of variables and, therefore, the quantitative phase of this study could not present information about the number of patients referred to a palliative care specialist, marital status, culture, and other important variables. In addition, the quantitative data examined was for the last hospital stay only and so there was no focus on other possible variables of interest such as repeat hospital admissions during the previous year, 30-day readmission rates, or transitions between care settings in the last year of life. Future research could examine these variables to further characterize hospital use by the 85+ age group.

The third limitation is that the qualitative phase of this study only examined the perceptions of adult children and not the perceptions of other family caregivers or formal caregivers. This focus was intentional as adult children may have very different perceptions than other people, including the surviving parent/spouse. Future studies should aim to identify differences and similarities between the perceptions of adult children and the spouses of advanced-age decedents in regards to the quality of EOL care. The fourth limitation is that participants reported on the EOL care received in hospitals in Southern Ontario. Therefore, the views shared may not be reflective of other areas of Ontario or outside of Ontario. Furthermore, recruitment could have been enhanced through the use of social media.

The study also had several strengths. First, this is the first study to examine advanced-age decedent hospital use in Ontario in detail. However, more research is needed to further characterize decedents who utilize the SCU, as it is possible that they could have or should have been saved if they had been admitted earlier. This study also highlighted the need to further examine the designation of ALC among patients who die in hospital to determine its association, if any, with clinician or family or patient recognition of approaching death and to identify the extent of need for alternative services in other care locations, such as LTC facilities or the patient's home.

The second strength of this study was the creation of a substantive theory for high-quality EOL care for dying advanced-age adults through adult children. The theory can be used as a framework to evaluate and teach important care components relating to quality EOL in hospital for advanced-age adults and perhaps also younger dying persons. This theory supports the present priorities in EOL care that have been outlined in Canada and other countries (CHPCA, 2015; Marie Currie, 2017; NCP, 2013; NHS Scotland, 2013).

Third, this study used a mixed methods research design. Findings elicited from the CIHI DAD highlighted important aspects of care which were explored in greater detail in the qualitative phase. As such, a greater understanding of quality EOL was realized.

Chapter Summary

This chapter provided a discussion of key findings derived from the quantitative and qualitative phases of this mixed methods research study. The integration of the two phases identified that the recognition of end of life in the advanced-age adults is an area that requires further investigation and improvement. Themes related to the substantive theory of high-quality EOL care for advanced-age adults were also discussed, and limitations and strengths of the study outlined.

CHAPTER SIX

RESEARCH SUMMARY AND IMPLICATIONS

Ensuring all Canadians have access to high-quality end-of-life (EOL) care is a national priority (Canadian Hospice Palliative Care Association [CHPCA], 2015; Quality End-of-Life Care Coalition of Canada, [QELCCC] 2010). While progress has been made toward meeting this priority (CHPCA, 2015), there is a growing body of evidence that suggests advanced-age adults (aged 85+) are at risk of receiving sub-optimal end-of-life (EOL) care and particularly in hospital (Gardiner et al., 2011; Lloyd et al., 2016; Unroe & Meier, 2013; Wenger & Rosenfeld, 2001). This is a growing concern, as advanced-age adults are the fastest growing population group in Canada (Statistics Canada, 2017c),

Moreover, adult children comprise the largest informal caregiver group in Canada (Sinha, 2013). As many adult children are baby boomers, they may be more critical of the quality of care provided to their older parents than previous generations (Guberman et al., 2006, 2012). As such, they are likely to have important critical insights about the health care their parents receive. Although it is also important to know the perceptions of other family caregivers, by understanding adult children's perceptions of the quality of hospital care received by their dying advanced-age parent, clinicians can implement quality improvement measures, target interventions, and respond to adult children needs accordingly. Chapter Six presents a summary of this study and outlines key recommendations.

Research Summary

This research study began with an extensive literature review about advanced-age decedents in Canada and quality EOL care. The review served as a background to focus and plan the study, and to design research questions. Two focused comprehensive literature reviews identified significant gaps in knowledge regarding the quality of EOL care received by dying advanced-age adults and adult children perceptions about the quality of EOL care received by their dying advanced-age parents in hospital. This research study addressed these knowledge gaps by using a quantitative-QUALITATIVE priority-sequence mixed methods research design (Morgan, 1998). In the first phase, the CIHI DAD covering the fiscal period April 2014 – March 2015 established socio-demographic, health, and hospital use information regarding advanced-age decedents who died in Ontario acute care hospitals. This phase established the context through using population-level hospital data and helped to plan the second phase. In this qualitative phase, a substantive theory of high-quality EOL hospital care for non-surgical hospital patients aged 85+ was developed through interviewing adult children about the care their recently deceased parent had received in hospital.

Chapter Four outlined key findings and Chapter Five discussed those findings. In summary, this study found 13,450 adults aged 85+ died in Ontario hospitals, with this number representing 38.7% of all advanced-age decedents who died in the 2014-2015 year in Ontario. The LOS was often short, with 75% dying within two weeks of hospital admission. They received few life-sustaining interventions in hospital, such as CPR and mechanical ventilation, and only 12.0% died in a SCU.

As expected, a slightly greater proportion of advanced-age hospital decedents were female, lived in urban areas, and came to hospital from a home. Most were admitted to hospital through the ER, received mostly medicine services, and almost half (47.4%) died in small community hospitals. The most frequent MRDx were diseases of the circulatory system, diseases of the respiratory system, and certain infections. One in five (21.1%) of all advanced-age decedents had a MRDx of palliative care, and only 17% of theses decedents who had a MRDx of palliative care were documented as having a known palliative care plan prior to hospital admission.

The sense of unpredictability identified in the quantitative phase of this mixed methods study was also evident in the qualitative phase. This study found although most parents were identified as DNR well in advance of their death, most children were still surprised that this hospitalization would end in death. A substantive theory of high-quality EOL care was developed, with themes of: (a) being an adult child, (b) being an advocate, (c) receiving high (and low) quality care at the end of life, and (d) reacting and remembering. This substantive theory emphasizes that high-quality EOL care for advanced-age parents in hospital consisted of being kept informed, compassionate care, dignity and respect, and optimal personal care and comfort measures.

This mixed method study demonstrated the value of combining both quantitative and qualitative methods in one study. Integrating results from the two phases demonstrated that death is often unpredictable in advanced-age adults and often met with surprise by their adult children. In addition, the great deal of nursing support needed to care for advanced-age adults at the end of life may exceed family resources. Therefore, once admitted to hospital, adult children are reliant on the hospital team to care for their dying parent. Adult children reported feeling responsible however to ensure their parent received good care, and therefore, expect hospital staff to respond accordingly. By understanding the perceptions of adult children, interventions can be targeted to meet the parent and family needs. This study thus demonstrated that using a mixed method approach provided a much greater understanding of quality EOL hospital care for dying advanced-age adults than one method could do alone.

Implications for Policy and Practice

This study identified several areas for quality improvement. Identified priority areas of improvement were ensuring sufficient palliative care resources are available, enhancing clinician recognition of dying and timely initiation of goals of care discussions, and the implementation of system approaches to enhance quality EOL care in hospital.

There is a need for more palliative and EOL care resources in hospitals as hospitals clearly are a place now and perhaps forever of death and dying. Therefore, the first implication is that all hospitals in Ontario should have access to a specialist palliative care team to ensure patients and their families receive high-quality EOL care from the specialist palliative care team or generalist care nurses and physicians trained and supported by them. At a minimum, the EOL care team should include a physician and a nurse who are specialized in the area of EOL care (Health Quality Ontario, 2014). The evidence shows that a team model improves patient comfort, quality of life, and family satisfaction (Health Quality Ontario, 2014).

The second implication is that EOL care expertise should also be developed among ER staff as the vast majority of dying advanced-age adults come in through the ER. Education could be focused on screening, identifying, and initiating palliative care referrals for ER patients in need of palliative care, and also on initiating goals of care discussions, and implementing comfort measures (Lamba & Mosenthal, 2012; Mierendorf & Gidvani, 2014). Clinical guidelines and screening tools could also be implemented to assist ER staff to care for patients potentially in need of palliative care (Lamba et al., 2014; Mierendorf & Gidvani, 2014; Registered Nurses of Ontario, 2011)

There is a need for increased recognition by all healthcare providers and family members of irrevocable dying states, so earlier EOL planning and care occurs. Therefore, the third implication is that research is needed to more clearly identify dying people, and processes need to be adopted to enable clinicians to identify people who could benefit from palliative care and to engage in care planning discussions (Baidoobonso, 2014; Ministry of Health and Long-Term Care, 2016b). All current healthcare providers need a course on early recognition of dying and goals of care discussions. Education should also be provided to family members. Research has shown that education for healthcare providers improves symptom control (Nevis, 2014). Education for informal caregivers also improves their quality of life and improves symptom control for their loved ones (Nevis, 2014; OHTAC End-of-Life Collaborative, 2014).

There is a need for a system-wide approach to EOL care for all dying persons in each province, so they get better quality EOL care in every setting, not just hospitals, and to help keep people out of hospital or get them home from hospital to die. Therefore, the fourth implications is that the healthcare system needs to be redesigned with patient-centered care provided. As such, the latter implication supports Ontario's current strategies. The recent $75M invested by the province to develop a comprehensive strategy for palliative and EOL care and the creation of the new Ontario Palliative Care Network are testaments of the province's commitment to this important work (Ministry of Health and Long-Term Care, 2016a). By examining certain populations, such as dying advanced-age adults and their families, targeted interventions can be created to improve the quality of EOL care received.

Chapter Summary

This mixed methods study emphasized that quality improvement is needed to enhance the quality of EOL care provided to advanced-age adults in hospitals. This chapter outlined four main implications for policy and practice as this study expanded the evidence base on advanced-age adults who die in acute care hospitals. This chapter concludes this research report.

References

Abarshi, E., Echteld, M., Van den Block, L., Donker, G., Deliens, L., & Onwuteaka-Philipsen, B. (2010). The oldest old and GP end-of-life care in the Dutch community: A nationwide study. *Age and Ageing, 39*(6), 716-722. doi:10.1093/ageing/afq097

Adams, J. A., Bailey, D. E., Anderson, R. A., & Docherty, S. I. (2011). Nursing roles and strategies in end-of-life decision-making in acute care: A systematic review of the literature. *Nursing Research and Practice, 2011.* doi:10.1155/2011/527834

Addington-Hall, J., Lay, M., Altmann, D., & McCarthy, M. (1995). Symptom control, communication with health professionals, and hospital care of stroke patients in the last year of life as reported by surviving family, friends, and officials. *Stroke, 26*(12), 2242-2248. doi:10.1161/01.STR.26.12.2242

Addington-Hall, J., & McPherson, C. (2001). After-death interviews with surrogates/bereaved family members: Some issues of validity. *Journal of Pain and Symptom Management, 22*(3), 784-790. doi:10.1016/S0885-3924(01)00330-X

Addington-Hall, J. M., & O'Callaghan, A. C. (2009). A comparison of the quality of care provided to cancer patients in the UK in the last three months of life in in-patient hospices compared with hospitals, from the perspective of bereaved relatives: Results from a survey using the VOICES questionnaire. *Palliative Medicine, 23*(3), 190-197. doi:10.1177/0269216309102525

Afzal, N., Buhagiar, K., Flood, J., & Cosgrave, M. (2009). Quality of end-of-life care for dementia patients during acute hospital admission: A retrospective study in Ireland. *General Hospital Psychiatry, 32*(2), 141-146. doi:10.1016/j.genhosppsych.2009.10.003

Agar, M., Currow, D. C., Shelby-James, T. M., Plummer, J., Sanderson, C., & Abernethy, A. P. (2008). Preference for place of care and place of death in palliative care: Are these different questions? *Palliative Medicine, 22*(7), 787-795. doi:10.1177/0269216308092287

Ahearn, D. J., Nidh, N., Kallat, A., Adenwala, Y., & Varman, S. (2013). Offering older hospitalised patients the choice to die in their preferred place. *Postgrad Medicine Journal, 89*(1047), 20-24. doi:10.1136/postgradmedj-2012-131161

Ahmad, S., & O'Mahony, M. S. (2005). Where older people die: A retrospective population-based study. *Quality Journal of Medicine, 98*(12), 865-870. doi:10.1093/qjmed/hci138

Ahronheim, J. C., Morrison, R. S., Baskin, S. A., Morris, J., & Meier, D. E. (1996). Treatment of the dying in the acute care hospital. Advanced dementia and metastatic cancer. *Archives of Internal Medicine, 156*(18), 2094-2100.

Alturki, M., & Khan, T. M., (2013). A study investigating the level of satisfaction with the health services provided by the pharmacist at ENT hospital, Eastern Region Alahsah, Kingdom of Saudi Arabia. *Saudi Pharmaceutical Journal, 21*(3), 255-260. doi:10.1016/j.jsps.2012.09.001

American Geriatrics Society Expert Panel on the Care of Older Adults with Multimorbidity. (2012). Guiding principles for the care of older adults with multimorbidity: An approach for clinicians. *Journal of the American Geriatrics Society, 60*(10), E1-E25. doi:10.1111/j.1532-5415.2012.04188.x

Andersson, M., Hallberg, I. R., & Edberg, A. (2007). Health care consumption and place of death among old people with public home care or in special accommodation in their last year of life. *Aging Clinical and Experimental Research, 19*(3), 228-239.

ANZSPM (2014). *Position Statement. Quality end-of-life care – Part 1. Essential elements for quality, safety and appropriate clinical care at the end of life*. Australia: The Australian and New Zealand Society of Palliative Medicine. Retrieved from http://palliativecarewa.asn.au/site/wp-content/uploads/2014/03/ANZSPM-Position-Statement-2014-on-Quality-End-of-Life-Care-Part-1-February.pdf

Aoun, S., Bird, S., Kristjanson, L. J., & Currow, D. (2010). Reliability testing of the FAMCARE-2 scale: Measuring family carer satisfaction with palliative care. *Palliative Medicine, 24*(7), 674-681. doi:10.1177/0269216310373166

Baidoobonso S. (2014). Patient care planning discussions for patients at the end of life: An evidence-based analysis. *Ontario Health Technology Assessment Series*, *14*(19):1–72. Retrieved from http://www.hqontario.ca/evidence/publications-and-ohtac-recommendations/ontario-health-technology-assessment-series/eol-planning-discussions

Bainbridge, D. & Seow, H. (2016). Measuring the quality of palliative care at end of life: An overview of data sources. *Healthy Aging & Clinical Care in the Elderly, 2016*(8), 9-15. doi:10.4137/HACCE.S18556

Baker, R., Wu, A. W., Teno, J. M., Kreling, B., Damiano, A. M., Rubin, H. R., . . . Lynn, J. (2000). Family satisfaction with end-of-life care in seriously ill hospitalized adults. *Journal of the American Geriatrics Society, 48*(5 Suppl), S61-69.

Beccaro, M., Caraceni, A., Costantini, M., & ISDOC Study Group (2009). End-of-life care in Italian hospitals: Quality of and satisfaction with care from the caregivers' point of view: Results from the Italian Survey of the Dying of Cancer. *Journal of Pain & Symptom Management, 39*(6), 1003-1015. doi:10.1016/j.jpainsymman.2009.11.317

Becker, G., Sarhatlic, R., Olschewski, M., Xander, C., Momm, F., & Blum, H. E. (2007). End-of-life care in hospital: Current practice and potentials for improvement. *Journal of Pain & Symptom Management, 33*(6), 711-719. doi:10.1016/j.jpainsymman.2006.09.030

Bell, D. C. & Richard, A. J. (2000). Caregiving: The forgotten element in attachment. *Psychological Inquiry, 11*(2), 69–83. doi:10.1207/S15327965PLI1102_01

Benzein, E., Norberg, A., & Saveman, B. I. (2001). The meaning of the lived experience of hope in patients with cancer in palliative home care. *Palliative Medicine, 15*, 117-126. doi: 10.1191/026921601675617254

Beyer, I., Compte, N., Busuioc, A., Cappelle, S., Lanoy, C., & Cytryn, E. (2010). Anemia and transfusions in geriatric patients: A time for evaluation. *Hematology, 15*(2), 116–121. doi:10.1179/102453310X12583347010052

Birks, M., Chapman, Y., & Francis, K. (2008). Memoing in qualitative research. *Journal of Research in Nursing, 13*(1), 68-75. doi:10.1177/1744987107081254

Birks, M., & Mills, J. (2011). *Grounded theory: A practical guide*. Thousand Oaks, CA: Sage Publications.

Bleich, S. N., Ozaltin, E., & Murray, C. K. L. (2009). How does satisfaction with the health-care system relate to patient experience? *Bulletin of the World Health Organization, 87*(4), 271-278. doi:10.2471/BLT.07.050401

Bloomer, M. J., Endacott, R., O'Connor, M., & Cross, W. (2013). The 'dis-ease' of dying: Challenges in nursing care of the dying in the acute hospital setting. A qualitative observational study. *Palliative Medicine, 27*(8), 757-764. doi:10.1177/0269216313477176

Boersma, I., Jones, J., Coughlan, C., Carter, J., Bekelman, D., Miyasaki, J., Kutner, J., & Kluger, B. (2017). Palliative care and Parkinson’s disease: Caregiver perspectives. *Journal of Palliative Medicine, 20*(9), 930–938. doi: 10.1089/jpm.2016.0325. Epub 2017 May 18.

Bravell, M. E., Malmberg, B., & Berg, S. (2010). End-of-life care in the oldest old. *Palliative & Supportive Care, 8*(3), 335-344. doi:10.1017/s1478951510000131

Brazil, K., Cupido, C., Taniguchi, A., Howard, M., Akhtar-Danesh, N., & Frolic, A. (2013). Assessing family members' satisfaction with information sharing and communication during hospital care at the end of life. *Journal of Palliative Medicine, 16*(1), 82-86. doi:10.1089/jpm.2012.0362

Bringer, J. D., Johnston, L. H., & Brackenridge, C. H. (2006). Using computer-assisted qualitative data analysis software to develop a grounded theory project. *Field Methods, 18*(3), 245-266. doi:10.1177/1525822X06287602

Bussmann, S., Muders, P., Zahrt-Omar, C. A., Escobar, P. L. C., Claus, M., Schildmann, J., & Weber, M. (2015). Improving end-of-life care in hospitals: A qualitative analysis of bereaved families’ experiences and suggestions. *American Journal of Hospice & Palliative Medicine, 32*(1), 44-51. doi:10.1177/1049909113512718

Cable-Williams, B. (2011). *The influence of long-term care culture on awareness of impending death*. (Doctoral Dissertation). University of Alberta: Edmonton, Alberta.

Canadian Hospice Palliative Care Association. (2015). *The Way Forward National Framework: A roadmap for an integrated palliative approach to care. The Way Forward Initiative.* Retrieved from http://www.hpcintegration.ca/media/60044/TWF-framework-doc-Eng-2015-final-April1.pdf

Canadian Institute for Health Information. (n.d.). *Definitions and guidelines to support ALC designation in acute inpatient care*. Retrieved from https://www.cihi.ca/en/acuteinpatientalc-definitionsandguidelines_en_corrected_-_en-web.pdf

Canadian Institute for Health Information. (2005). *Data quality of the Discharge Abstract Database following the first-year implementation of the ICD-10-CA/CCI: Final report.* Retrieved from https://secure.cihi.ca/estore/productSeries.htm?locale=en&pc=PCC228

Canadian Institute for Health Information. (2006). *Improving the health of Canadians: An introduction to health in urban places*. Canadian Population Health Initiative. Retrieved from https://secure.cihi.ca/free_products/PH_Full_Report_English.pdf

Canadian Institute for Health Information. (2007). *Health care use at the end of life in Western Canada.* Retrieved from https://secure.cihi.ca/free_products/end_of_life_report_aug07_e.pdf

Canadian Institute for Health Information. (2009). *Alternative level of care in Canada. Analysis in Brief.* Retrieved from https://secure.cihi.ca/free_products/ALC_AIB_FINAL.pdf

Canadian Institute for Health Information. (2011). *Health care use at the end of life in Atlantic Canada provinces.* Retrieved from https://secure.cihi.ca/free_products/end_of_life_2011_en.pdf

Canadian Institute for Health Information. (2012). *CIHI data quality study of the 2009–2010 Discharge abstract database: Revised 2012.* Retrieved from https://secure.cihi.ca/free_products/Reabstraction_june19revised_09_10_en.pdf

Canadian Institute for Health Information. (2013). *End-of-life hospital care for cancer patients.* Retrieved from https://secure.cihi.ca/free_products/Cancer_Report_EN_web_April2013.pdf

Canadian Institute for Health Information. (2014a). *Hospital deaths in Canada: 2013-2014*. Canadian Institute of Health Information. Retrieved from https://www.cihi.ca/web/resource/en/hsmr_2014_pubsum_en.pdf

Canadian Institute for Health Information. (2014b). *Discharge abstract database (DAD) metadata.* Retrieved from http://www.cihi.ca/CIHI-ext-portal/internet/en/document/types+of+care/hospital+care/acute+care/dad_metadata

Canadian Institute for Health Information. (2014c). *Education roadmap: Reach your GOAL with classifications, DAD, NACRS, and Case Mix*. Retrieved from http://www.cihi.ca/cihi-ext-portal/pdf/internet/class_education_roadmap_en

Canadian Institute for Health Information. (2014d). *ICD-10*. Ottawa, ON: Canadian Institute for Health Information. Retrieved from http://www.cihi.ca/cihi-ext-portal/internet/en/document/standards+and+data+submission/standards/classification+and+coding/codingclass_icd10

Canadian Institute for Health Information. (2014e). *Standards and data submission, data abstracting manual, 2014 – 2015 Edition*. CIHI: Ottawa, ON.

Canadian Institute for Health Information. (CIHI, 2014 – 2015). *DAD data elements*. Retrieved from https://www.cihi.ca/en/dad_data_elements_2014_2015_en.pdf

Canadian Institute for Health Information. (2015). *Canadian coding standards for version 2015 ICD-10-CA and CCI.* Ottawa, ON: Canadian Institute for Health Information. Retrieved from https://secure.cihi.ca/free_products/Coding%20standard_EN_web.pdf

Canadian Institute for Health Information. (2016). *Indicator library: Peer group methodology, Methodology Note*s. Retrieved from indicatorlibrary.cihi.ca/download/attachments/.../Peer-Group-Methodology_EN.pdf

Cancer Quality Council of Ontario. (2016). End-of-life care measures. Retrieved from http://www.csqi.on.ca/cms/One.aspx?portalId=351209&pageId=354850

Carpenter, B. D. (2001). Attachment bonds between adult daughters and their older mothers: Associations with contemporary caregiving. *Journal of Gerontology: Psychological Sciences, 56b*(5), 257–266. doi:10.1093/geronb/56.5.P257

Carstairs, S. (2005). *Still not there. Quality end-of-life care: A progress report.* Retrieved from http://www.chpca.net/media/7883/Still_Not_There_June_2005.pdf

Casey, D., Murphy, K., Ni Leime, A., Larkin, P., Payne, S., Froggatt, K. A., & O'Shea, E. (2011). Dying well: Factors that influence the provision of good end-of-life care for older people in acute and long-stay care settings in Ireland. *Journal of Clinical Nursing, 20*(13-14), 1824-1833. doi:10.1111/j.1365-2702.2010.03628.x

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis.* London: Sage Publications.

Charmaz, K. (2014). *Constructing grounded theory* (2 ed.). Los Angeles, CA: Sage Publications.

Chasen, M., & Dosani, N. (2015). Are patients receiving the right care in the right place at the right time? *Current Oncology, 22*(5), 315–314. doi:10.3747/co.22.2912

Clarke, A., & Ross, H. (2005). Influences on nurses' communications with older people at the end of life: Perceptions and experiences of nurses working in palliative care and general medicine. *International Journal of Older People Nursing, 1*(1), 34-43. doi:10.1111/j.1748-3743.2006.00006.x

Cohen, C. C., Auslander, G., & Chen, Y. (2010). Family caregiving to hospitalized end-of-life and acutely ill geriatric patients. *Journal of Gerontological Nursing, 36*(8), 42–50. doi:10.3928/00989134-20100330-03

Cohen, C. C., Auslander, G., Dror, Y. F., & Breuer, G. S. (2016). Functional and existential tasks of family caregiving for end-of-life, hospitalized older adults. *Journal of Gerontological Nursing, 42*(7), 55–64. doi:10.3928/00989134-20160406-04

Committee on Care at the End of Life, Institute of Medicine (1997). *Approaching Death: Improving Care at the End of Life.* M. J. Field & C. K. Cassel (Eds.), Retrieved from http://www.nap.edu/catalog/5801/approaching-death-improving-care-at-the-end-of-life

Cook, I., Kirup, A. L., Langham, L. J., Malik, M. A., Marlow, G., & Sammy, I. (2017). End of life care and do not resuscitate orders: How much does age influence decision making? A systematic review and meta-analysis. *Gerontology & Geriatric Medicine, 3,* 1–17. doi:10.11/2333721217713422

Cook, D., & Rocker, G. (2013). End-of-life care in Canada: A report from the Canadian Academy of Health Sciences Forum. *Clinical Investigations in Medicine, 36*(3), E122.

Corbin, J., & Morse, J. M. (2003). The unstructured interactive interview: Issues of reciprocity and risks when dealing with sensitive topics. *Qualitative Inquiry, 9*(3), 335-354. doi:10.1177/1077800403009003001

Coventry, P. A., Grande, G. E., Richards, D. A., & Todd, C. J. (2005). Prediction of appropriate timing of palliative care for older adults with non-malignant life-threatening disease: A systematic review. *Age and Ageing, 34*(3), 218-227. doi:10.1093/aging/afi054

Creswell, J. W. (2013). *Qualitative inquiry & research design: Choosing among five approaches* (3rd ed.). Los Angeles: Sage.

Creswell, J. W., & Plano Clark, V. L. (2011). *Designing and conducting mixed methods research* (2nd ed.). London: Sage.

Davies, E., & Higginson, I. J. (2004). *Better palliative care for older people*. Retrieved from http://www.euro.who.int/__data/assets/pdf_file/0009/98235/E82933.pdf

de Witt, L., & Ploeg, J. (2006). Critical appraisal of rigour in interpretive phenomenological nursing research. *Journal of Advanced Nursing, 55*(2), 215-229. doi:10.1111/j.1365-2648.2006.03898.x

Dellinger, A. B., & Leech, N. L. (2007). Toward a unified validation framework in mixed methods research. *Journal of Mixed Methods Research, 1*(4), 302-332. doi:10.1177/1558689807306147

Dendaas, N., Pellino, T. A., Roberts, K. F., & Cleary, J. (2001). Responding to SUPPORT: An academic medical center examines its end-of-life care practices. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. *Journal of Pain & Symptom Management, 21*(2), 121-128. doi:10.1016/S0885-3924(00)00257-8

Detering, K. M., Hancock, A. D., Reade, M. C., & Silvester, W. (2010). The impact of advance care planning on end of life care in elderly patients: Randomised controlled trial. *British Medical Journal, 340,* 1-9. doi:10.1136/bmj.c1345

Dodek, P. M., Heyland, D. K., Rocker, G. M., & Cook, D. J. (2004). Translating family satisfaction data into quality improvement. *Critical Care Medicine, 32*(9), 1922-1927. doi:10.1097/01.CCM.0000139920.53790.61

Donabedian, A. (1988). The quality of care: How can it be assessed? *Journal of the American Medical Association, 260*(12), 1743-1748. doi:10.1001/jama.1988.03410120089033

Donnelly, S., & Battley, J. (2010). Relatives' experience of the moment of death in a tertiary referral hospital. *Mortality, 15*(1), 81-100. doi:10.1080/13576270903537641

Dose, A. M., Carey, E. C., Rhudy, L. M., Chiu, Y., Frimannsdottir, K., Ottenberg, A. L., & Koenig, B. A. (2015). Dying in the hospital: Perspectives of family members. *Journal of Palliative Care, 31*(1), 13–20. doi:10.1177/082585971503100103

Duggleby, W., Penz, K. L., Goodridge, D. M., Wilson, D. M., Leipert, B. D., Berry, P. H., . . . Justice, C. J. (2010). The transition experience of rural older persons with advanced cancer and their families: A grounded theory study. *BMC Palliative Care, 9*(5). doi:10.1186/1472-684X-9-5

Dy, S. M., Kiley, K. B., Ast, K., Lupu, D., Norton, S. A., McMillan, S. C.,…Casarett, D. J. (2015). Measuring what matters: Top-ranked quality indicators for hospice and palliative care from the American Academy of Hospice and Palliative Medicine and Hospice and Palliative Nurses Association. *Journal of Pain and Symptom Management, 49*(1), 773–781. doi:10.1016/j.jpainsymman.2015.01.012

Dy, S. M., Shugarman, L. R., Lorenz, K. A., Mularski, R. A., & Lynn, J. (2008). A systematic review of satisfaction with care at the end of life. *Journal of the American Geriatrics Society, 56*(1), 124-129. doi: 10.1111/j.1532-5415.2007.01507.x

Engelberg, R. A., Downey, L., Wenrich, M. D., Carline, J. D., Silvestri, G. A., Dotolo, D., . . . Curtis, J. R. (2010). Measuring the quality of end-of-life care. *Journal of Pain & Symptom Management, 39*(6), 951-971. doi:10.1016/j.jpainsymman.2009.11.313

Esteve, A., Jimenez, C., Perez, R., & Gomez, J. A. (2009). Factors related to withholding life-sustaining treatment in hospitalized elders. *Journal of Nutrition, Health & Aging, 13*(7), 644-650. doi:10.1007/s12603-009-0176-9

Fakhoury, W. K., McCarthy, M., & Addington-Hall, J. (1997). Carers' health status: Is it associated with their evaluation of the quality of palliative care? *Scandinavian Journal of Social Medicine, 25*(4), 296-301. doi:10.1177/140349489702500413

Ferrell, B., Connor, S. R., Cordex, A., Dahlin, C. M., Fine, P. G., Hutton, N., …Zuroski, K. (2007). The national agenda for quality palliative care: The national consensus project and the national quality forum. *Journal of Pain and Symptom Management, 33*(6), 737–744. doi:10.1016/j.jpainsymman.2007.02.024

Ferris, F. D., Balfour, H. M., Bowen, K., Farley, J., Hardwick, M., Lamontagne, C., . . . West, P. J. (2002). *A model to guide hospice palliative care: Based on national principles and norms of practice*. Retrieved from http://www.chpca.net/media/7422/a-model-to-guide-hospice-palliative-care-2002-urlupdate-august2005.pdf

Field, A. (2009). *Discovering statistics using SPSS.* Los Angeles: Sage.

Fins, J. J., Miller, F. G., Acres, C. A., Bacchetta, M. D., Huzzard, L. L., & Rapkin, B. D. (1999). End-of-life decision-making in the hospital: Current practice and future prospects. *Journal of Pain & Symptom Management, 17*(1), 6-15. doi:10.1016/S0885-3924(98)00109-2

Fleming, J., Farquhar, M., Cambridge City over-75s Cohort (CC75C) study collaboration, Brayne, C., & Barclay, S. (2016). Death and the oldest old: Attitudes and preferences for end-of-life care - Qualitative research within a population-based cohort study. *PLoS ONE, 11*(4): e0150686. doi:10.1371/journal.pone.0150686

Fleming, J., Zhao, J., Farquhar, M., Brayne, C., Barclay, C., Barclay, S., & the Cambridge City over-75s Cohort (CC75C) study collaboration. (2010). Place of death for the 'oldest old':

≥ 85-year-olds in the CC75C population-based cohort. *British Journal of General Practice, 60*(573), 171-179. doi:10.3399/bjgp10X483959

Footman, K., Roberts, B., Mills, A., Richardson, E., & McKee, M. (2013). Public satisfaction as a measure of health system performance: A study of nine countries in the former Soviet Union. *Health Policy, 112*(1–2), 62-69. doi:10.1016/j.healthpol. 2013.03.004

Formiga, F., Olmedo, C., Lopez-Soto, A., Navarro, M., Culla, A., & Pujol, R. (2007). Dying in hospital of terminal heart failure or severe dementia: The circumstances associated with death and the opinions of caregivers. *Palliative Medicine, 21*(1), 35-40. doi:10.1177/0269216306073256

Fowler, R., & Hammer, M. (2013). End-of-life care in Canada. *Clinical & Investigative Medicine, 36*(3), E127-E132. doi:10.25011/cim.v36i3.19723

Frank, C., Touw, M., Suurdt, J., Jiang, X., Wattam, P., & Heyland, D. K. (2012). Optimizing end-of-life care on medical clinical teaching units using the CANHELP questionnaire and a nurse facilitator: A feasibility-study. *Canadian Journal of Nursing Research, 44*(1), 41-58.

Fuchs, L., Anstey, M., Feng, M., Toledano, R., Kogan S., Howell, M. D.,…Novack, V. (2017). Quantifying the mortality impact of do-not-resuscitate orders in the ICU. *The Society of Critical Care Medicine and Wolters Kluwer Health, Inc., 45*(6). doi:10.1097/CCM.0000000000002312

Gagnon, J., & Duggleby, W. (2014). The provision of end-of-life care by medical-surgical nurses working in acute care: A literature review. *Palliative & Supportive Care, 12*(5), 393-408. doi:10.1017/S1478951513000965

Galanos, A. N., Morris, D. A., Pieper, C. F., Poppe-Ries, A. M., & Steinhauser, K. E. (2012). End-of-life care at an academic medical center: Are attending physicians, house staff, nurses, and bereaved family members equally satisfied? Implications for palliative care. *American Journal of Hospice & Palliative Medicine, 29*(1), 47-52. doi:10.1177/1049909111407176

Gao, W., Ho., Y. K., Verne, J., Glickman, M., & Higginson, I. J. (2013). Changing patterns in place of cancer death in England: A population-based study. *PLoS Medicine,* Retrieved from https://doi.org/10.1371/journal.pmed.1001410

Gardiner, C., Cobb, M., Gott, M., & Ingleton, C. (2011). Barriers to providing palliative care for older people in acute care hospitals. *Age and Ageing, 40*(2), 233-238. doi:10.1093/ageing/afq172

Gardiner, C., Gott, M., Ingleton, C., & Richards, N. (2013). Palliative care for frail older people: A cross-sectional survey of patients at two hospitals in England. *Progress in Palliative Care, 21*(5), 272–277. doi:10.1179/1743291X12Y.0000000043

Garner, K. K., Goodwin, J. A., McSweeney, J. C., & Kirchner, J. E. (2013). Nurse executives' perceptions of end-of-life care provided in hospitals. *Journal of Pain & Symptom Management, 45*(2), 235-243. doi:10.1016/j.jpainsymman.2012.02.021

Giesbrecht, M., Crooks, V. A., Williams, A., & Hankivsky, O. (2012). Critically examining diversity in end-of-life family caregiving: Implications for equitable caregiver support and Canada's Compassionate Care Benefit. *International Journal for Equity in Health, 11*(65). Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3502300/pdf/1475-9276-11-65.pdf

Gill, C., Hillier, L., Crandall, J., & Johnson, J. (2010). Nursing guidelines for end-of-life care in long-term care settings: Sustainable improvements to care. *Journal of Palliative Care, 27*(3), 229-237.

Glaser, B. G., & Strauss, A. L. (1968). *Time for dying*. Chicago: Aldine Publishing.

Gomes, B., Cohen, J., Deliens, L., & Higginson, I. J. (2011). International trends in circumstances of death and dying amongst older people. In M. Gott & C. Ingleton (Eds.), *Living with ageing and dying: Palliative and end of life care for older people*. (pp. 3-18). New York, USA: Oxford University Press.

Goodlin, S. J., Winzelberg, G. S., Teno, J. M., Whedon, M., & Lynn, J. (1998). Death in hospital. *Archives of Internal Medicine, 158*(14), 1570-1572. doi:10.1001/ archinte.158.14.1570

Gott, M., Barnes, S., Parker, C., Payne, S., Seamark, D., Gariballa, S., & Small, N. (2007). Dying trajectories in heart failure. *Palliative Medicine, 21*(2), 95-99. doi:10.1177/0269216307076348

Gott, M., Seymour, J., Bellamy, G., Clark, D., & Ahmedzai, S. (2004). Older people's views about home as a place of care at the end of life. *Palliative Medicine, 18*(5), 460-467. doi:10.1191/0269216304pm889oa

Government of Ontario. (2017). *Aging with confidence: Ontario's action plan for Seniors.* Retrieved from https://files.ontario.ca/ontarios_seniors_strategy_2017.pdf

Gradwohl, R., & Brant, J. M. (2015). Hospital-based palliative care: Quality metrics that matter. *Journal of Advances Practice Oncology, 6*(6), 606–610. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5017551/pdf/jadp-06-606.pdf

Grande, G., & Keady, J. (2011). Needs, access, support for older carers. In M. Gott & C. Ingleton (Eds.), *Living with ageing and dying: Palliative and end of life care for older people*. New York, USA: Oxford University Press.

Guberman, N., Lavoie, J.-P., Blein, L., & Olazabal, I. (2012). Baby boom caregivers: Care in the age of individualization. *The Gerontologist, 52*(2), 210-218. doi:10.1093/geront/gnr140

Guberman, N., Lavoie, J.-P., Fournier, M., Grenier, L., Gagnon, E., Belleau, H., & Vezina, A. (2006). Families' values and attitudes regarding responsibility for the frail elderly: Implications for aging policy. *Journal of Aging & Social Policy, 18*(3-4), 59-78. doi:10.1300/J031v18n03_05

Hall, S., Petkova, H., Tsouros, A. D., Costantini, M., & Higginson, I. J. (2011). *Better palliative care for older people: Better practices*. Copenhagen, Denmark: World Health Organization Regional Office for Europe. Retrieved from http://www.euro.who.int/__data/assets/pdf_file/0017/143153/e95052.pdf.

Hanson, L. C., Scheunemann, L. P., Zimmerman, S., Rokoske, F. S., & Schenck, A. P. (2010). The PEACE project review of clinical instruments for hospice and palliative care. *Journal of Palliative Care, 13*(10), 1253–1260. doi: 10.89/jpm.2010.0194

Hawker, S., Kerr, C., Payne, S., Seamark, D., Davis, C., Roberts, H., . . . Smith, H. (2006). End-of-life care in community hospitals: The perceptions of bereaved family members. *Palliative Medicine, 20*(5), 541-547. doi:10.1191/0269216306pm1170oa

Health Quality Ontario. (2014). Team-based models for end-of-life care: An evidence-based analysis. *Ontario Health Technology Assessment Series*, *14*(20):1–49. Retrieved from http://www.hqontario.ca/evidence/publications-and-ohtac-recommendations/ontario-health-technology-assessment-series/eol-team-based-models

Health Quality Ontario & Ontario Palliative Care Network. (2018). *Quality standards: Palliative care-Care for adults with a progressive, life-limiting illness*. Health Quality Ontario. Toronto: Queen's Printer for Ontario.

Hesse, K. A. (1995). Terminal care of the very old: Changes in the way we die. *Archives of Internal Medicine, 155*(14), 1513-1518. doi:10.1001/archinte.1995.00430140086009

Heyland, D. K., Allan, D. E., Rocker, G., Dodek, P., Pichora, D., Gafni, A., & Canadian Researchers at the End-of-Life Network (2009). Discussing prognosis with patients and their families near the end of life: Impact on satisfaction with end-of-life care. *Open Medicine: A Peer-reviewed, Independent, Open-access Journal, 3*(2), e101-110. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2765767/

Heyland, D. K., Barwich, D., Pichora, D., Dodek, P., Lamontagne, F., You, J. J., . . . Canadian Researchers at the End of Life Network. (2013). Failure to engage hospitalized elderly patients and their families in advance care planning. *Journal of the American Medical Association, Internal Medicine, 173*(9), 778-787. doi:10.1001/jamainternmed.2013.180

Heyland, D. K., Cook, D. J., Rocker, G. M., Dodek, P. M., Kutsogiannis, D. J., Skrobik, Y., . . . Canadian Researchers at the End of Life Network. (2010a). Defining priorities for improving end-of-life care in Canada. *Canadian Medical Association Journal, 182*(16), E747-752. doi:10.1503/cmaj.100131

Heyland, D. K., Cook, D. J., Rocker, G. M., Dodek, P. M., Kutsogiannis, D. J., Skrobik, Y., . . . Cohen, S. R. (2010b). The development and validation of a novel questionnaire to measure patient and family satisfaction with end-of-life care: The Canadian Health Care Evaluation Project (CANHELP) Questionnaire. *Palliative Medicine, 24*(7), 682-695. doi:10.1177/0269216310373168

Heyland, D. K., Dodek, P., Rocker, G., Groll, D., Gafni, A., Pichora, D., . . . Canadian Researchers End-of-Life Network. (2006). What matters most in end-of-life care: Perceptions of seriously ill patients and their family members. *Canadian Medical Association Journal, 174*(5), 627-633. doi:10.1503/cmaj.050626

Heyland, D. K., Frank, C., Tranmer, J., Paul, N., Pichora, D., Jiang, X., & Day, A. G. (2009). Satisfaction with end-of-life care: A longitudinal study of patients and their family caregivers in the last months of life. *Journal of Palliative Care, 25*(4), 245-256.

Heyland, D. K., Groll, D., Rocker, G., Dodek, P., Gafni, A., Tranmer, J., …Canadian Researchers at the End of Life Network (CARENET). (2005). End-of-life care in acute care hospitals in Canada: A quality finish? *Journal of Palliative Care, 21*(3), 142-150.

Heyland, D. K., Jiang, X., Day, A. G., & Cohen, S. R. (2013). The development and validation of a shorter version of the Canadian health care evaluation project questionnaire (CANHELP): A novel tool to measure patient and family satisfaction with end-of-life care. *Journal of Pain and Symptom Management, 46*(2), 289-297. doi:10.1016/j.jpainsymman.2012.07.012

Heyland, D. K., Lavery, J. V., Tranmer, J. E., & Shortt, S. E. D. (2000a). The final days: An analysis of the dying experience in Ontario. *Annales CRMCC, 33*(6), 356-361.

Heyland, D. K., Lavery, J. V., Tranmer, J. E., Shortt, S. E. D., & Taylor, S. J. (2000b). Dying in Canada: Is it an institutionalized, technologically supported experience? *Journal of Palliative Care, 16*, S10-16.

Houttekier, D., Cohen, J., Pepersack, T., & Deliens, L. (2013). Dying in hospital: A study of incidence and factors related to hospital death using death certificate data. *European Journal of Public Health, 24*(5), 751–756. doi:10.1093/eurpub/ckt209

Howell, D., & Brazil, K. (2005). Reaching a common ground: A patient-family based conceptual framework on quality end-of-life care. *Journal of Palliative Care, 21*(1), 19-26.

Huijberts, S., Buurman, B. M., & de Rooij, S. E. (2016). End-of-life care during and after an acute hospitalization in older patients with cancer, end-stage organ failure, or frailty: A sub-analysis of a prospective cohort study. *Palliative Medicine, 30*(1), 75-82. doi:10.77/0269216315606010

Hunt, K. J., Shlomo, N., & Addington-Hall, J. (2014a). End-of-life care and preferences for place of death among the oldest old: Results of a population-based survey using VOICES-Short Form. *Journal of Palliative Medicine, 17*(2), 176-182. doi:10.1089/jpm.2013.0385

Hunt, K. J., Shlomo, N., & Addington-Hall, J. (2014b). End-of-life care and preferences for place of death in England: Results of a population-based survey using VOICES-SF questionnaire. *Journal of Palliative Medicine, 28*(5), 412-421. doi:10.1177/0269216313512012

Hynson, J. L., Aroni, R., Bauld, C., & Sawyer, S. M. (2006). Research with bereaved parents: A question of how not why. *Palliative Medicine, 20*(8), 805-811. doi:10.1177/0269216306072349

IBM Corp (2015). IBM SPSS Statistics for Windows, Version 23.0. Armonk, NY: IBM Corp.

Izumi, S., Nagae, H., Sakurai, C., & Imamura, E. (2012). Defining end-of-life care from perspectives of nursing ethics. *Nursing Ethics, 19*(5), 608-618. doi:10.1177/0969733011436205

Jacobs, L. G., Bonuck, K., Burton, W., & Mulvihill, M. (2002). Hospital care at the end of life: An institutional assessment. *Journal of Pain & Symptom Management, 24*(3), 291-298. doi:10.1016/S0885-3924(02)00494-3

James, I., Andershed, B., & Ternestedt, B. M. (2009). The encounter between informal and professional care at the end of life. *Qualitative Health Research, 19*(2), 258-271. doi:10.1177/1049732308329309

Johnson, R. B., Onwuegbuzie, A. J., & Turner, L. A. (2007). Toward a definition of mixed methods research. *Journal of Mixed Methods Research, 1*(2), 112-133. doi:10.1177/1558689806298224

Kamra, V., Singh, H., & Kumar, K. (2015). Factors affecting patient satisfaction: An exploratory study for quality management in the heath-care sector. *Total Quality Management & Business*, *27*(9-10), 1013-1027, doi:10.1080/14783363.2015.1057488

Karantzas, G. C., Evans, L., & Foddy, M. (2010). The role of attachment in current and future parent caregiving. *Journal of Gerontology: Psychological Sciences, 65B*(5), 573–580. doi:10.1093/geronb/gbq047

Kelley, A. S., Ettner, S. L., Wenger, N. S., & Sarkisian, C. A. (2011). Determinants of death in the hospital among older adults. *Journal of the American Geriatrics Society, 59*(12), 2321-2325. doi: 0.1111/j.1532-5415.2011.03718.x

Kirkpatrick, J. N. (2015). Goals of care discussions: How hard can it be? *Journal of the American Medical Association, Internal Medicine, 175*(4), 557–558. doi:10.1001/jamainternmed.2014.7740

Kvale, S. (1996). *Interviews: An introduction to qualitative research interviewing*. Thousand Oaks, CA: Sage.

Lamba, S., DeSandre, P. L., Todd, K. H., Bryant, E. N., Chan, G. K., Grudzen, C. R.,…Quest, T. E. (2014). Integration of palliative care into emergency medicine: The improving palliative care in emergency medicine (IPAL-EM) Collaboration. *The Journal of Emergency Medicine, 46*(2), 264 - 270. doi: 10/1016/j.jemermed.2013.08.087

Lamba, S., & Mosenthal, A.C. (2012). Hospice and palliative medicine: A novel subspecialty of emergency medicine. *The Journal of Emergency Medicine*, *43*(5), 849–853. doi:10.1016/j.jemermed.2010.04.010

Leadership Alliance for the Care of Dying People. (2014). *One chance to get it right: Improving people's experience of care in the last few days and hours of life.* Retrieved from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf

Leech, N. L., & Onwuegbuzie, A. J. (2009). A typology of mixed methods research designs. *Quality & Quantity Journal, 43*(2), 265-275. doi:10.1007/s11135-007-9105-3

Lehan Mackin, M., Herr, K., Bergen-Jackson, K., Fine, P., Forcucci, C., & Sanders, S. (2009). Research participation by older adults at end of life: Barriers and solutions. *Research in Gerontological Nursing, 2*(3), 162-171. doi:10.3928/19404921-20090421-05

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.

Lincolnshire Community Health Services NHS Trust. (2015). The five priorities for care of the dying person (Adult): Lincolnshire Guidelines. Retrieved from https://www.lincolnshirecommunityhealthservices.nhs.uk/application/files/1915/1386/7755/G_CS_72_Five_priorities_for_care_of_the_dying_person_adult_-_Lincolnshire_Guidelines.pdf

Lloyd, A., Kendall, M., Carduff, E., Cavers, D., Kimbell, B., & Murray, S.A. (2016). Why do older people get less palliative care than younger people? *European Journal of Palliative Care, 23*(3), 132–137. Retrieved from https://www.ed.ac.uk/files/atoms/files/lloyd_a_et_al_why_do_older_people_get_less_palliative_care.watermark_copy.pdf

Lloyd-Williams, M., Kennedy, V., Sixsmith, A., & Sixsmith, J. (2007). The end of life: A qualitative study of the perceptions of people over the age of 80 on issues surrounding death and dying. *Journal of Pain and Symptom Management, 34*(1), 60-66. doi:10.1016/j.jpainsymman.2006.09.058

Local Health Integration Networks & Quality Hospice Palliative Care Coalition of Ontario (2011). *Advancing high quality, high value palliative care in Ontario: A declaration of partnership and commitment to action.* Retrieved from http://health.gov.on.ca/en/public/programs/ltc/docs/palliative%20care_report.pdf

London, M. R., & Lundstedt, J. (2007). Families speak about inpatient end-of-life care. *Journal of Nursing Care Quality, 22*(2), 152-158. doi:10.1097/01.NCQ.0000263105.08096.b1

Loopstra, C., Strodl, E., & Herd, D. (2015). A qualitative analysis of how parents assess acute pain in young children. *Health Psychology Open, 2*(1). doi:10.1177/2055102914566290

Lunney, J. R., Lynn, J., Foley, D. J., Lipson, S., & Guralnik, J. M. (2003). Patterns of functional decline at the end of life. *Journal of the American Medical Association, 289*(18), 2387-2392. doi:10.1001/jama.289.18.2387

Lunney, J. R., Lynn, J., & Hogan, C. (2002). Profiles of older medicare decedents. *Journal of the American Geriatrics Society, 50*(6), 1108-1112. doi:10.1046/j.1532-5415.2002.50268.x

Lynn, J., Teno, J. M., Phillips, R. S., Wu, A. W., Desbiens, N., Harrold, J., . . . Connors, A. F., Jr. (1997). Perceptions by family members of the dying experience of older and seriously ill patients. SUPPORT Investigators. Study to Understand Prognoses and Preferences for

Outcomes and Risks of Treatments. *Annals of Internal Medicine, 126*(2), 97-106. doi:10.7326/0003-4819-126-2-199701150-00001

Malterud, K. (2012). Systematic text condensation: A strategy for qualitative analysis. *Scandinavian Journal of Public Health, 40*(8), 795-805. doi:10.1177/1403494812465030

Marie Curie (2017). What does high quality end of life care look like? *Palliative Care Knowledge Zone.* Retrieved from https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/what-does-high-quality-end-of-life-care-look-like

Maxwell, J. A. (2013). *Qualitative research design: An interactive approach* (3rd ed.). California: Sage.

McCosker, H., Barnard, A., & Gerber, R. (2001). Undertaking sensitive research: Issues and strategies for meeting the safety needs of all participants. *Forum: Qualitative Social Research, 2*(1), 1-10. doi:10.17169/fqs-2.1.983

McIlvennan, C. K. & Allen, L. A. (2016). Palliative care in patients with heart failure. *British Medical Journal, 2016*(353). doi:10.1136/bmj.i1010. Retrieved from http://wwpalliativecare.ca/Uploads/ContentDocuments/BMJ%20Review%202016.pdf

McPherson, C. J., & Addington-Hall, J. M. (2003). Judging the quality of care at the end of life: Can proxies provide reliable information? *Social Science & Medicine, 56*(1), 95-109. doi:10.1016/S0277-9536(02)00011-4

Meier, E. A., Gallegos, J. V., Montross-Thomas, L. P., Depp, C. A., Irwin, S. A., & Jeste, D. V. (2016). Defining a good death (successful dying): Literature review and a call for research and public dialogue. *American Journal of Geriatric Psychiatry, 24*(4), 261–271. doi:10.1016/j.jagp.2016.01.135

Menec, V. H., Lix, L., Nowicki, S., & Ekuma, O. (2007). Health care use at the end of life among older adults: Does it vary by age? *Journal of Gerontology, Series A, 62*(4), 400-407. doi:10.1093/gerona/62.4.400

Merriam, S. B. (2002). Assessing and evaluating qualitative research. In S. B. Merriam and Associates (Eds.), *Qualitative research in practice: Examples for discussion and analysis* (pp. 18-33). San Francisco: Jossey-Bass.

Meyer, R. W. (2000). Commentary: Measuring quality of care at the end of life: who? when? where? and how? *Western Journal of Medicine, 172*(6), 377-378. doi:10.1093/geront/42.suppl_3.71

Middlewood, S., Gardner, G., & Gardner, A. (2001). Dying in hospital: Medical failure or natural outcome? *Journal of Pain & Symptom Management, 22*(6), 1035-1041. doi:10.1016/S0885-3924(01)00362-1

Mierendorf, S. M., & Gidvani, V. (2014). Palliative care in the emergency department. *The Permanente Journal, 18*(2), 77-85. doi:10.7812/TPP/13-103

Mills, J., Bonner, A., & Francis, K. (2006a). Adopting a constructivist approach to grounded theory: Implications for research design. *International Journal of Nursing Practice, 12*(1), 8-13. doi:10.1111/j.1440-172X.2006.00543

Mills, J., Bonner, A., & Francis, K. (2006b). The development of constructivist grounded theory. *International Journal of Qualitative Methods, 5*(1), 25-35. doi: 10.1177/160940690600500103

Ministry of Health and Long-Term Care. (2016a). Ontario strengthening access to end-of-life care: Province announces funding increase to hospices as part of $75 million investment.

News Release. Retrieved from https://news.ontario.ca/mohltc/en/2016/06/ontario-strengthening-access-to-end-of-life-care.html

Ministry of Health and Long-Term Care. (2016b). *Palliative Care: Follow-up on VFM Section 3.08, 2014 Annual Report*. Retrieved from http://www.auditor.on.ca/en/content/annualreports/arreports/en16/v2_108en16.pdf

Ministry of Health & Long Term Care. (2017). *Alternative level of care (ALC) days. Resource for Indicator Standards (RIS).* Health Analytics Branch, Ministry of Health and Long Term Care. Retrieved from http://www.health.gov.on.ca/en/pro/programs/ris/docs/alternate_level_of_care_days_en.pdf

Moon, H., & Dilworth-Anderson, P. E. (2015). Baby boomer caregiver and dementia caregiving: Findings from the National Study of Caregiving. *Age and Ageing, 44*(2), 300-306. doi:10.1093/ageing/afu119

Moran-Ellis, J., Alexander, V. D., Cronin, A., Dickinson, M., Fielding, J., Sleney., J., & Thomas, H. (2006). Triangulation and integration: Processes, claims and implications. *Qualitative Research, 6*(1), 45-59. doi:10.1177/1468794106058870

Morgan, D. (1998). Practical strategies for combining qualitative and quantitative methods: Application to health research. *Qualitative Health Research, 8*(3), 362-376. doi:10.1177/104973239800800307

Morita, T., Hirai, K., Sakaguchi, Y., Maeyama, E., Tsuneto, S., Shima, Y., & Quality Assurance Committee, Japanese Association of Hospice and Palliative Care Units (2004). Measuring the quality of structure and process in end-of-life care from the bereaved family perspective. *Journal of Pain & Symptom Management, 27*(6), 492-501. doi:10.1016/j.jpainsymman.2003.10.014

Morrison, R. S. (2013). Research priorities in geriatric palliative care: An introduction to a new series. *Journal of Palliative Medicine, 16*(7), 726-729. doi:10.1089/jpm.2013.9499

Moss, A. H. (2016). Chapter 19: Palliative care in patients with kidney disease and cancer. *Onco-Nephrology Curriculum. American Society of Nephrology.* Retrieved from https://www.asn-online.org/education/distancelearning/curricula/onco/Chapter19.pdf

Moyano, J., Zambrano, S., & Mayungo, T. (2010). Characteristics of the last hospital stay in terminal patients at an acute care hospital in Colombia. *American Journal of Hospice & Palliative Medicine, 27*(6), 402-406. doi:10.1177/1049909110362522

Mularski, R. A. (2006). Defining and measuring quality palliative and end-of-life care in the intensive care unit. *Critical Care Medicine, 34*(11 Suppl), S309-316. doi:10.1097/01.CCM.0000241067.84361.46

Mularski, R. A., Dy, S. M., Shugarman, L. R., Wilkinson, A. M., Lynn, J., Shekelle, P. G., . . . Lorenz, K. A. (2007). A systematic review of measures of end-of-life care and its outcomes. *Health Services Research, 42*(5), 1848-1870. doi:10.1111/j.1475-6773.2007.00721.x

Murray, M. A., Fiset, V., Young, S., & Kryworuchko, J. (2009). Where the dying live: A systematic review of the determinants of place of end-of-life cancer care. *Oncology Nursing Forum, 36*(1), 69-77. doi:10.1188/09.ONF.69-77

Nadimi, F., & Currow, D. C. (2011). As death approaches: A retrospective survey of the care of adults dying in Alice Springs Hospital. *Australian Journal of Rural Health, 19*(1), 4-8. doi:10.1111/j.1440-1584.2010.01169.x

Natan, M. B., Garfinkel, D., & Shachar, I. (2010). End-of-life needs as perceived by terminally ill older adult patients, family and staff. *European Journal of Oncology Nursing, 14*(4), 299-303. doi:10.1016/j.ejon.2010.05.002

National Consensus Project for Quality Palliative Care (2013). *Clinical Practice Guidelines for Quality Palliative Care,* 3rd Edition. Retrieved from https://www.nationalcoalitionhpc.org/ncp-guidelines-2013/

Nelson, J. E., Puntillo, K. A., Pronovost, P. J., Walker, A. S., McAdam, J. L., Ilaoa, D., & Penrod, J. (2010). In their own words: Patients and families define high-quality palliative care in the intensive care unit. *Critical Care Medicine, 38*(3), 808-818. doi:10.1097/CCM.0b013e3181c5887c

Nevis I. (2014). Educational intervention in end-of-life care: An evidence-based analysis. *Ontario Health Technology Assess Series,14*(17), 1–30. Retrieved from: http://www.hqontario.ca/evidence/publications-and-ohtac-recommendations/ontario-health-technology-assessment-series/eol-educational-interventions

Newman, E., Risch, E., & Kassam-Adams, N. (2006). Ethical issues in trauma-related research: A review. *Journal of Empirical Research on Human Research Ethics*, *1*(3), 29-46. doi:10.1525/jer.2006.1.3.29

NHS Scotland. (2013). *Palliative and end of life care: Indicators.* Retrieved from http://www.healthcareimprovementscotland.org/our_work/patient_experience/palliative_care/palliative_care_indicators.aspx

Northcott, H. C., & Wilson, D. M. (2016). *Dying and death in Canada*, (3rd Ed.). New York: University of Toronto Press.

NVIVO. (2016). NVivo qualitative data analysis software; QSR International Pty Ltd. Version 11.

O'Shea, M. F. (2014). Staff nurses' perceptions regarding palliative care for hospitalized older adults. *American Journal of Nursing, 114*(11), 26-34; quiz 35, 44. doi:10.1097/01.NAJ.0000456424.02398.ef

Odgers, J., Fitzpatrick, D., Penney, W., & Wong Shee, A. (2018). No one said he was dying: Families' experiences of end-of-life care in an acute setting. *Australian Journal of Advanced Nursing, 35*(3), 21-31. Retrieved from http://www.ajan.com.au/Vol35/Issue3/3Odgers.pdf

OECD Data (2016). *Length of hospital stay. Organisation for Economic Co-operation and Development.* Retrieved from https://data.oecd.org/healthcare/length-of-hospital-stay.htm

Ogasawara, C., Kume, Y., & Andou, M. (2003). Family satisfaction with perception of and barriers to terminal care in Japan. *Oncology Nursing Forum, 30*(5), E100-105. doi:10.1188/03.ONF.E100-E105

Ohta, B., & Kronenfeld, J. J. (2011). Intensity of acute care services at the end of life: Nonclinical determinants of treatment variation in an older adult population. *Journal of Palliative Medicine, 14*(6), 722-728. doi:10.1089/jpm.2010.0360

OHTAC End-of-Life Collaborative. (2014). Health care for people approaching the end of life: An evidentiary framework. *Ontario Health Technology Assessment Series, 14*(14), 1-45. Retrieved from http://www.hqontario.ca/Portals/0/Documents/eds/ohtas/recommendation-eol-1411-en.pdf

Oktay, J. S. (2012). *Grounded theory*. New York, NY: Oxford University Press.

Oladjide, O., Hanson, L., Usher, B. M., Qaqish, B. F., Schwartz, R., & Bernard, S. (2007). Validation of the palliative performance scale in the acute tertiary care hospital setting. *Journal of Palliative Medicine, 10*(1), 111–117. doi:10.1089/jpm.2006.0125

Olden, A. M., Holloway, R., Ladwig, S., Quill, T. E., & van Wijngaarden, E. (2011). Palliative care needs and symptom patterns of hospitalized elders referred for consultation. *Journal of Pain and Symptom Management, 42*(3), 410-418. doi:10.1016/j.jpainsymman.2010.12.005

Ontario Ministry of Finance. (2015). *Ontario population projections, 2013 - 2041*. Oshawa, ON: Ministry of Finance. Retrieved from http://www.fin.gov.on.ca/en/economy/demographics/projections/projections2013-2041.pdf.

Onwuegbuzie, A. J., & Johnson, R. B. (2006). The validity issue in mixed research. *Research in the Schools, 13*(1), 48-63. Retrieved from http://www.msera.org/docs/rits-v13n1-complete.pdf#page=55

Onwuegbuzie, A. J., & Leech, N. L. (2005). On becoming a pragmatic researcher: The importance of combining quantitative and qualitative research methodologies. *International Journal of Social Research Methodology, 8*(5), 375-387. doi:10.1080/13645570500402447

Paice, J. A., Muir, J. C., & Shott, S. (2004). Palliative care at the end of life: Comparing quality in diverse settings. *American Journal of Hospice & Palliative Medicine, 21*(1), 19-27. doi:10.1177/104990910402100107

Parkes, C. M. (1995). Guidelines for conducting ethical bereavement research. *Death Studies, 19*(2), 171-181. doi:10.1080/07481189508252723

Patton, M. Q. (2002). *Qualitative research & evaluation methods* (3 ed.). Thousand Oaks, CA: Sage Publications.

Payne, S., Hawker, S., Kerr, C., Seamark, D., Roberts, H., Jarrett, N., & Smith, H. (2007). Experiences of end-of-life care in community hospitals. *Health & Social Care in the Community, 15*(5), 494-501. doi:10.1111/j.1365-2524.2007.00714.x

Phua, J., Chin-Leong, A., Tan, A., Mukhopadhyay, A., Choong See, K., Wah Aung, N., Seah, A. S. T., & Keang Lim, T. (2011). End-of-life care in the general wards of a Singaporean hospital: An Asian perspective. *Journal of Palliative Medicine, 14*(12), 1296-1301. doi:10.1089/jpm.2011.0215

Pierce, S. F. (1999). Improving end-of-life care: Gathering suggestions from family members. *Nursing Forum, 34*(2), 5-14. doi:10.1111/j.1744-6198.1999.tb00981.x

Pinquart, M., & Sorensen, S. (2011). Spouses, adult children, and children-in-law as caregivers of older adults: A meta-analytic comparison. *American Psychological Association, 26*(1), 1-14. doi:10.1037/a0021863

Pivodic, L., Pardon, K., Morin, L., Addington-Hall, J., Miccinesi, G., Cardenas-Turanzas, M., …Cohen, J. (2016). Place of death in the population dying from diseases indicative of palliative care need: A cross-national population-level study in 14 countries. *Journal of Epidemiology and Community Health, 70*(1)*,* 17–24. doi:10.1136/jech-2014-205365

Pocock, L. V., Ives, A., Pring, A., Verne, J., & Purdy, S. (2016). Factors associated with hospital deaths in the oldest old: A cross-sectional study. *Age and Ageing, 45*(3)*,* 375-376. doi:10.1093/ageing/afw019

Quality End-of-Life Care Coalition of Canada. (2010) *Blueprint for Action 2010 to 2020.* Ottawa, ON. Retrieved from http://www.qelccc.ca/media/3743/blueprint_for_action_2010_to_2020_april_2010.pdf

Registered Nurses' Association of Ontario. (2011). *End of life care during the last days and hours.* Toronto, ON: Registered Nurses' Association of Ontario. Retrieved from http://rnao.ca/bpg/guidelines/endoflife-care-during-last-days-and-hours

Reyneirs, T., Deliens, L., Pasman, R., Vander Stichele, R., Sijnave, B., Cohen, J., & Houttekier, D. (2016). Reasons for end-of-life hospital admissions: Results of a survey among family physicians. *Journal of Pain and Symptom Management, 52*(2), 498-506. doi:10.1016/j.jpainsymman.2016.05.014

Rosenblatt, P. C. (1995). Ethics of qualitative interviewing with grieving families. *Death Studies, 19*(2), 139-155. doi:10.1080/07481189508252721

Roze des Ordons, A., Sharma, N., Heyland, D. K., & You, J. J. (2015). Strategies for effective goals of care discussions and decision-making: Perspectives from a multi-centre survey of Canadian hospital-based healthcare providers. *BMC Palliative Care, 14*(38). doi:10.1186/s129.4-015-0035-x

Sadler, E., Hales, B., Henry, B., Xiong, W., Myers, J., Wynnychuk, L., . . . Fowler, R. (2014). Factors affecting family satisfaction with inpatient end-of-life care. *PLoS ONE, 9*(11), e110860. doi:10.1371/journal.pone.0110860

Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science, 8*(3), 27-37. doi: 10.1097/00012272-198604000-00005

Sbaraini, A., Carter, S. M., Evans, R. W., & Blinkhorn, A. (2011). How to do a grounded theory study: A worked example of a study of dental practices. *BMC Medical Research Methodology, 11*(128). doi:10.1186/1471-2288-11-128

Schenck, A. P., Rokoske, F. S., Durham, D., Cagle, J. G., & Hanson, L. C. (2010). The PEACE project: Identification of quality measures for hospice and palliative care. *Journal of Palliative Medicine, 13*(12), 1452–1459. doi: 1089/jpm.2010.0238

Seah, S. T. A., Low, J. A., & Chan, Y. H. (2005). Symptoms and care of dying elderly patients in an acute hospital. *Singapore Medical Journal, 46*(5), 210-214. Retrieved from http://www.sma.org.sg/smj/4605/4605a1.pdf

Seow, H., Bainbridge, D., Brouwers, M., Pond, G., & Cairney, J. (2017). Validation of a modified VOICES survey to measure end-of-life care quality: the CaregiverVoice survey. *BMC Palliative Care, 16*(44). doi:10.1186/s12904-017-0227-7

Seow, H., Bainbridge, D., Bryant, D., Guthrie, D., Urowitz, S., Zwicker, V., & Marshall, D. (2016). The CaregiverVoice Survey: A pilot study surveying bereaved caregivers to measure the caregiver and patient experience at end of life. *Journal of Palliative Medicine, 19*(7), 712- 719. doi: 10.1089/jpm.2015.0366

Seow, H., Brazil, K., Sussman, J., Pereira, J., Marshall, D., Austin, P. C.,…Barbera, L. (2014). Impact of community based, specialist palliative care teams on hospitalisations and emergency department visits late in life and hospital deaths: A pooled analysis. *British Medical Journal.* 348:g3496. doi:http://doi.org/10.1136/bmj.g3496

Sheward, K., Clark, J., Marshall, B., & Allan, S. (2011). Staff perceptions of end-of-life care in the acute care setting: A New Zealand perspective. *Journal of Palliative Medicine, 14*(5), 623-630. doi:10.1089/jpm.2010.0470

Sikolia, D., Biros, D., Mason, M., & Weiser, M. (2013). Trustworthiness of grounded theory methodology research in information systems. *MWAIS Proceedings*. Retrieved from http://aisel.aisnet.org/cgi/viewcontent.cgi?article=1006&context=mwais2013

Sinclair, S., Norris, J. M., McConnell, S. J., Chochinov, H. M., Hack, R. F., Hagen, N. A., …Bouchal, S., R. (2016). Compassion: A scoping review of the literature. *BMC Palliative Care, 15*(6). doi:10.1186/s12904-016-0080-0

Singer, P. A., Martin, D. K., & Kelner, M. (1999). Quality end-of-life: Patients' perspectives. *Journal of the American Medical Association, 281*(2), 163-168. doi:10.1001/jama.281.2.163

Sinha, M. (2013). *Portrait of caregivers, 2012*. (89-652-X). Ottawa: ON: Statistics Canada. Retrieved from http://www.statcan.gc.ca/pub/89-652-x/89-652-x2013001-eng.htm

Somogyi-Zalud, E., Zhong, Z., Hamel, M. B., & Lynn, J. (2002). The use of life-sustaining treatments in hospitalized persons aged 80 and older. *Journal of the American Geriatrics Society, 50*(5), 930-934. doi:10.1046/j.1532-5415.2002.50222.x

Somogyi-Zalud, E., Zhong, Z., Lynn, J., & Hamel, M. B. (2000). Elderly persons' last six months of life: Findings from the Hospitalized Elderly Longitudinal Project. *Journal of the American Geriatrics Society, 48*(5 Suppl), S131-139.

Stajduhar, K. I. (2013). Burdens of family caregiving at the end of life. *Clinical & Investigative Medicine, 36*(3), E121-E126.

Stajduhar, K. I., Allan, D. E., Cohen, S. R., & Heyland, D. K. (2008). Preferences for location of death of seriously ill hospitalized patients: Perspectives from Canadian patients and their family caregivers. *Palliative Medicine, 22*(1), 85-88. doi:10.1177/ 0269216307084612

Stajduhar, K. I., Funk, L., Cohen, S. R., Williams, A., Bidgood, D., Allan, D., . . . Heyland, D. (2011). Bereaved family members' assessments of the quality of end-of-life care: What is important? *Journal of Palliative Care, 27*(4), 261-269. Retrieved from http://soignantfindevie.com/media/4836/Stajduhar-et-al-2011-Bereaved-family-members-assessments-of-the-quality-of-end-of-life-care-What-is-important.pdf

Statistics Canada. (2013). Deaths in hospital and elsewhere, Canada, provinces and territories. Ottawa, ON: Statistics Canada. Retrieved from http://www5.statcan.gc.ca/cansim/a26?lang=eng&retrLang=eng&id=1020509&paSer=&pattern=&stByVal=1&p1=1&p2=-1&tabMode=dataTable&csid=

Statistics Canada. (2017a). Table 051-0002 - *Estimates of deaths, by sex and age group, Canada, provinces and territories, annual (persons), CANSIM (database).* Retrieved from http://www5.statcan.gc.ca/cansim/a47

Statistics Canada. (2017b). *Deaths, by marital status, age group and sex, Canada, provinces and territories.* Table 102-0505. Retrieved from http://www5.statcan.gc.ca/cansim/a26?lang=eng&id=1020505

Statistics Canada. (2017c). *Census in Brief: A portrait of the population aged 85 and older in 2016 in Canada. Census of Population 2016.* Retrieved from http://www12.statcan.gc.ca/census-recensement/2016/as-sa/98-200-x/2016004/98-200-x2016004-eng.cfm

Statistics Canada. (2017d). Table 102-0504 - *Deaths and mortality rates, by age group and sex, Canada, provinces and territories, annual, CANSIM (database).* Retrieved from http://www5.statcan.gc.ca/cansim/a47

Statistics Canada. (2017e). *Leading causes of death, total population, by age group and sex, Canada.* Table 102-0561. Retrieved from http://www5.statcan.gc.ca/cansim/a47

Steindal, S. A., Ranhoff, A. H., Bredal, I. S., Sorbye, L. W., & Lerdal, A. (2013). Last three days of life in the hospital: A comparison of symptoms, signs and treatments in the young old and the oldest old patients using the resident assessment instrument for palliative care. *International Journal of Older People Nursing, 8*(3), 199-206. doi:10.1111/j.1748-3743.2012.00313.x

Steinhauser, K. E., Clipp, E., C., McNeilly, M., Christakis, N. A., McIntyre, L., M., & Tulsky, J. A. (2000). In search of a good death: Observations of patients, families, and providers. *Annals of Internal Medicine, 132*(10), 825-832. doi:10.7326/0003-4819-132-10-200005160-00011

Steinhauser, K. E., Voils, C. I., Bosworth, H., & Tulsky, J. A. (2015). What constitutes quality of family experience at the end of life? Perspectives from family members of patients who died in the hospital. *Palliative and Supportive Care, 13*(4), 945-952. doi:10.1017/S1478951514000807

Stroebe, M., Stroebe, W., & Schut, H. (2003). Bereavement research: Methodological issues and ethical concerns. *Palliative Medicine, 17*(3), 235-240. doi:10.1191/0269216303pm768rr

SUPPORT Investigators. (1995). A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). The SUPPORT Principal Investigators. *Journal of the American Medical Association, 274*(20), 1591-1598. doi:10.1001/jama.1995.03530200027032

Tabloski, P. A. (2014). *Gerontological nursing*. New Jersey: Pearson Education.

Tanuseputro, P., Budhwani, S., Qing Bai, Y., & Wodchis, W. P. (2017). Palliative care delivery across health sectors: A population-level observational study. *Palliative Medicine, 31*(3), 247–257. doi:10.1177/0269216316653524

Tanuseputro, P., Wodchis, W.P., Fowler, R., Walker, P., Qing Bai, Y., Bronskill, S. E., & Manuel, D. (2015). The health care cost of dying: A population-based retrospective cohort study of the last year of life in Ontario, Canada. *PLoS One, 10*(3), doi:10.1371/journal.pone.0121759

Teno, J. M., Casey, V. A., Welch, L. C., & Edgman-Levitan, S. (2001). Patient-focused, family-centered end-of-life medical care: Views of the guidelines and bereaved family members. *Journal of Pain & Symptom Management, 22*(3), 738-751. doi:10.1016/S0885-3924(01)00335-9

Teno, J. M., Clarridge, B., Casey, V., Edgeman-Levitan, S., & Fowler, J. (2001). Validation of Toolkit after-death bereaved family member interview. *Journal of Pain and Symptom Management, 22*(3), 752–758. doi:10.1016/S0885-3924(01)00331-1

Teno, J. M., Clarridge, B. R., Casey, V., Welch, L. C., Wetle, T., Shield, R., & Mor, V. (2004). Family perspectives on end-of-life care at the last place of care. *Journal of the American Medical Association, 291*(1), 88-93. doi:10.1001/jama.291.1.88

Teno, J. M., Weitzen, S., Fennell, M. L., & Mor, V. (2001). Dying trajectory in the last year of life: Does cancer trajectory fit other diseases. *Journal of Palliative Medicine, 4*(4), 457-464. doi:10.1089/109662101753381593

The Gold Standards Framework (2011). *The GSF prognostic indicator guidance: The National GSF Centre's guidance for clinician's to support earlier recognition of patients nearing the end of life.* Retrieved from https://www.goldstandardsframework.org.uk/cdcontent/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf

Thompson, G., & McClement, S. (2002). Defining and determining quality in end-of-life care. *International Journal of Palliative Nursing, 8*(6), 288-293. doi:10.12968/ijpn.2002.8.6.10499

Thompson, G., McClement, S., & Daeninck, P. (2006a). Nurses' perceptions of quality end-of-life care on an acute medical ward. *Journal of Advanced Nursing, 53*(2), 169-177. doi:10.1111/j.1365-2648.2006.03712.x

Thompson, G. N., McClement, S. E., & Daeninck, P. J. (2006b). "Changing lanes": Facilitating the transition from curative to palliative care. *Journal of Palliative Care, 22*(2), 91-98.

Thurston, A. J., Wilson, D. M., & Hewitt, J. A. (2011). Current end-of-life care needs and care practices in acute care hospitals. *Nursing Research and Practice*, *2011*:869302, doi:10.1155/2011/869302

Toscani, F., Di Giulio, P., Brunelli, C., Miccinesi, G., Laquintana, D., & End-of-Life Observatory Group. (2005). How people die in hospital general wards: A descriptive study. *Journal of Pain & Symptom Management, 30*(1), 33-40. doi:10.1016/j.jpainsymman.2005.01.013

Tschirhart, E. C., Du, Q., & Kelley, A. S. (2014). Factors influencing the use of intensive procedures at the end of life. *Journal of the American Geriatrics Association, 62*(11), 2088-2094. doi:10.1111/jgs.13104

Twomey, F., McDowell, D. K., & Corcoran, G. D. (2007). End-of-life care for older patients dying in an acute general hospital: Can we do better? *Age and Ageing Journal*, *36*(4), 462-464. doi:10.1093/ageing/afm031

Unroe, K. T., & Meier, D. E. (2013). Research priorities in geriatric palliative care: Policy initiatives. *Journal of Palliative Medicine, 16*(12), 1503-1508. doi:10.1089/jpm.2013.9464

Urden, L. D. (2002). Patient satisfaction measurement: Current issues and implications. *Outcomes Management, 6*(3), 125-131.

Verhofstede, R., Smets, T., Cohen, J., Costantini, M., Van Den Noortgate, N., & Deliens, L. (2016). Implementing the care programme for the last days of life in an acute geriatric hospital ward: A phase 2 mixed method study. *BMC Palliative Care*, *15*(27). doi:10.1186/s12904-016-0102-y

Verhofstede, R., Smets, T., Cohen, J., Eecloo, K., Costantini, M., Van Den Noortgate, N., & Deliens, L. (2017). End-of-life care and quality of dying in 23 acute geriatric hospital wards in Flanders, Belgium. *Journal of Pain and Symptom Management, 54*(4), 693-702. Retrieved from http://dx.doi.org/10.1016/j.jpainsymman.2016.10.363

Wallerstedt, B., & Andershed, B. (2007). Caring for dying patients outside special palliative care settings: Experiences from a nursing perspective. *Scandinavian Journal of Caring Sciences, 21*(1), 32-40. doi:10.1111/j.1471-6712.2007.00430.x

Ward-Griffen, C. (2004). Nurses as caregivers of elderly relatives: Negotiating personal and professional boundaries. *Canadian Journal of Nursing Research, 36*(1), 92–144.

Ward-Griffen, C., Brown, J. B., St-Amant, O., Sutherland, N., Martin-Matthews, A., Keefe, J., & Kerr, M. (2015). Nurses negotiating professional-familial care boundaries: Striving for balance within double duty caregiving. *Journal of Family Nursing, 21*(1), 57–85. doi:10.1177/1074840714562645

Weissman, D. E., & Meier, D. E. (2011). Identifying patients in need of a palliative care assessment in the hospital setting: A consensus report from the Center to Advance Palliative Care. *Journal of Palliative Medicine, 14*(1), 17-23. doi:10.1089/jpm.2010.0347

Weissman, D. E., Morrison, S., & Meier, D. E. (2010). Center to Advance Palliative Care palliative care clinical care and customer satisfaction metrics: Consensus recommendations. *Journal of Palliative Medicine, 13*(2), 179-184. doi:10.1089/jpm.2009.0270

Wenger, N. S., & Rosenfeld, K. (2001). Quality indicators for end-of-life care in vulnerable elders. *Annals of Internal Medicine, 135*(8), 677-685. doi:10.7326/0003-4819-135-8_Part_2-200110161-00006

Willard, C., & Luker, K. (2006). Challenges to end of life care in the acute hospital setting. *Palliative Medicine, 20*(6), 611-615. doi:10.1177/0269216306071064

Williams, B. R., Woodby, L. L., Bailey, F. A., & Burgio, K. L. (2008). Identifying and responding to ethical and methodological issues in after-death interviews with next-of-kin. *Death Studies, 32*(3), 197-236. doi:10.1080/07481180701881297

Wilson, D. M. (1997). A report of an investigation of end-of-life care practices in health care facilities and the influences on those practices. *Journal of Palliative Care, 13*(4), 34-40.

Wilson, D. M., Cohen, J., Deliens, L., Hewitt, J. A., & Houttekier, D. (2013). The preferred place of last days: Results of a representative population-based public survey. *Journal of Palliative Medicine, 16*(5), 502-508. doi:10.1089/jpm.2012.0262

Wilson, D. M., Cohen, J., MacLeod, R., & Houttekier, D. (2018). Bereavement grief: A population-based foundational evidence study. *Death Studies*, *42*(7), 463-469. doi:10.1080/07481187.2017.1382609

Wilson, D. M., & Hewitt, J. A. (2017). A scoping research literature review to assess the state of existing evidence on the "bad" death. *Palliative and Supportive Care, 16*(1), 90-106. doi:10.1017/S1478951517000530

Wilson, D. M., Hewitt, J. A., Thomas, R. E., & Woytowich, B. (2014). Why did an out-of-hospital shift occur in Canada after 1994? *International Journal of Palliative Care, 2014*:157536. doi:10.1155/2014/157536

Wilson, D. M., Shen, Y., & Birch, S. (2017). New evidence on end-of-life hospital utilization for enhanced health policy and services planning. *Journal of Palliative Medicine, 20*(7), 752-758. doi:10.1089/jpm.2016.0490

Wilson, D. M., & Truman, C. D. (2002). Addressing myths about end-of-life care: Research into use of acute care hospitals over the last five years of life. *Journal of Palliative Care, 18*(1), 29-38.

Wilson, D. M., Truman, C. D., Thomas, R., Fainsinger, R., Kovacs-Burns, K., Froggatt, K., & Justice, C. (2009). The rapidly changing location of death in Canada, 1994-2004. *Social Science & Medicine, 68*(10), 1752-1758. doi:10.1016/ j.socscimed.2009.03.006

World Health Organization (2018). *Canada statistics.* Retrieved from http://www.who.int/countries/can/en/

You, J. J., Dodek, P., Lamontagne, F., Downar, J., Sinuff, T., Jiang, X., . . . the Canadian Researchers at the End of Life Network. (2014). What really matters in end-of-life discussions? Perspectives of patients in hospital with serious illness and their families. *Canadian Medical Association Journal, 186*(18), E679-687. doi:10.1503/cmaj.140673

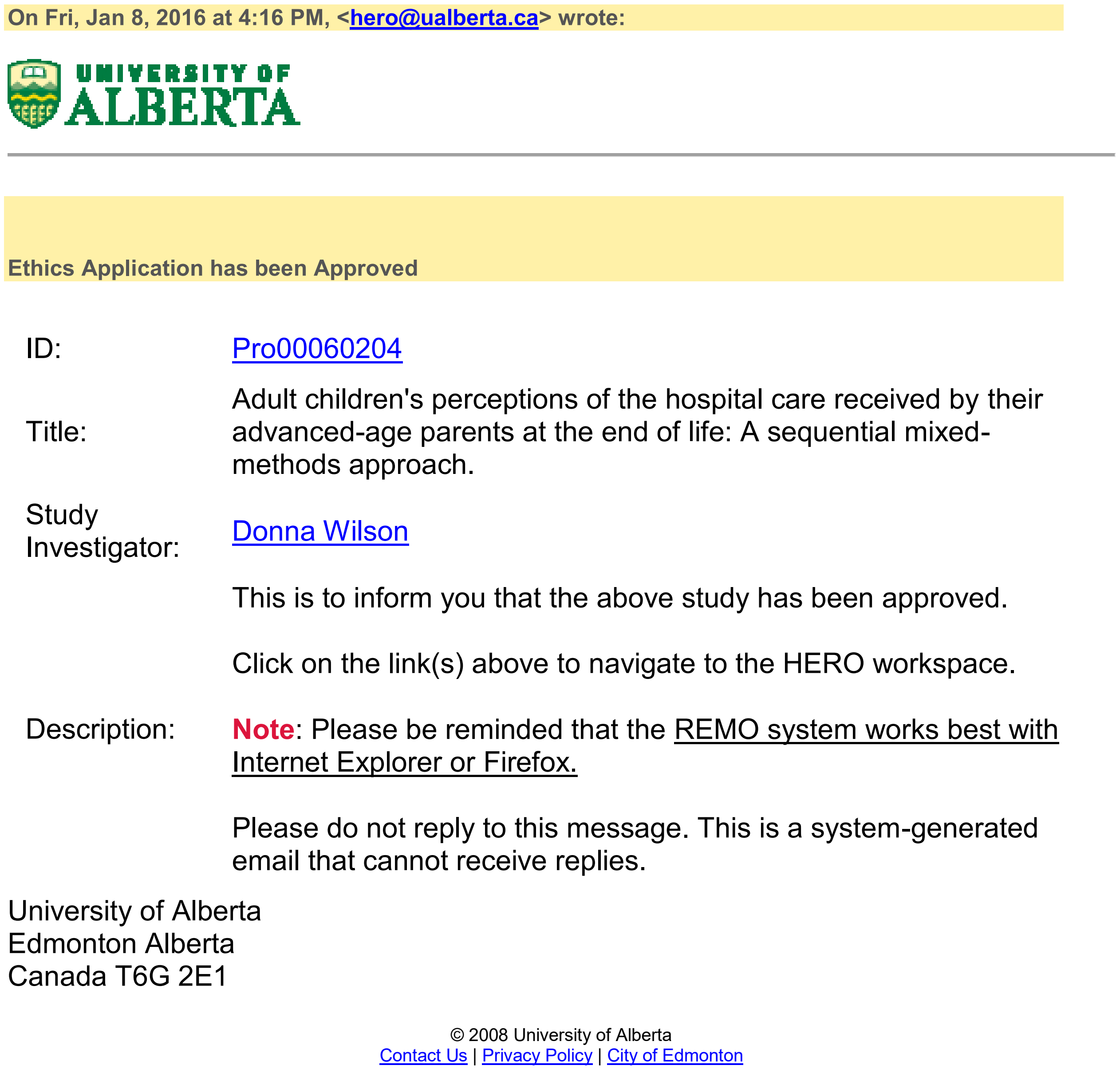
You, J. J., Downar, J., Fowler, R. A., Lamontagne, F., Ma, I. W. Y., Jayaraman, D…Heyland, D. K. (2015). Barriers to goals of care discussions with seriously ill hospitalized patients and their families: A multicenter survey of clinicians. *Journal of the American Medical Association, Internal Medicine, 174*(4), 549–556. Retrieved from https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/2107609?=

You, J. J., Fowler, R. A., & Heyland, D. K. (2014). Just ask: Discussing goals of care with patients in hospital with serious illness. *Canadian Medical Association Journal, 186*(6), 425–432. doi:10.1503/cmaj.121274

Young, A. J., Rogers, A., Dent, L., & Addington-Hall, J. M. (2009). Experiences of hospital care reported by bereaved relatives of patients after a stroke: A retrospective survey using the VOICES questionnaire. *Journal of Advanced Nursing, 65*(10), 2161-2174. doi:10.1111/j.1365-2648.2009.05081.x

Appendix A

Notice of Ethics Approval



On Fri, Jan 8, 2016 at 4:16 PM, <hero@ualberta.ca> wrote:

UNIVERSITY OF
ALBERTA

Ethics Application has been Approved

ID:	Pro00060204
Title:	Adult children's perceptions of the hospital care received by their advanced-age parents at the end of life: A sequential mixed-methods approach.
Study Investigator:	Donna Wilson
	This is to inform you that the above study has been approved. Click on the link(s) above to navigate to the HERO workspace.
Description:	**Note**: Please be reminded that the REMO system works best with Internet Explorer or Firefox. 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

Contact Us | Privacy Policy | City of Edmonton

Appendix B

Sample Recruitment Letter

Dear Sir/Madame:

I am writing to extend my condolences to you and your family on the loss of your parent. I would like to talk to you and invite you to take part in a research study regarding quality end-of-life care. First, I must apologize in advance should this letter cause you to experience any distress. I also assure you that the hospital has not released your contact information to me; instead, the (name of hospital) has sent this letter on my behalf for the purposes of the research study.

I am a nurse practitioner in the city of London and a graduate student in the Faculty of Nursing at the University of Alberta. I am dedicated to quality end-of-life care. The purpose of my research is to explore adult children's perceptions in relation to the hospital care received by their parent aged 85 and over. My aim is to develop a theory of high quality end-of-life hospital care for this population.

Your involvement is very important. Talking to family members about the care their parent received can help us understand your experience and develop interventions to enhance care. Participation in this research study is completely voluntary and confidential. If you decide to participate, you will be asked to complete a short 5-minute questionnaire and be interviewed once or twice for approximately 60 to 90 minutes. You may also be asked to participate in a focus group once initial interviews are complete. As a thank you for your time, you will be invited to a presentation that highlights the results of the study.

If you are interested in taking part in this study or would like to ask questions, please call me at ___________________ or email me at ______________________. Once again, I wish to extend my sincere condolences on the loss of your parent/loved one. I have included information in this letter about the grieving process as well as a link to resources in the community.

Sincerely,

Jacqueline Crandall, RN(EC), M.Sc.N.
University of Alberta, Faculty of Nursing

Appendix C

Sample Poster

Research Opportunity

Have you experienced the death of a parent aged 85 or over during an admission to an acute care hospital?

If you

- Are 18 years of age or older
- Experienced the death of a parent, step-parent, or adoptive parent aged 85 years and over within the past two years
- Assisted your parent to make decisions regarding health care matters
- Are willing to be interviewed on up to two occasions and participate in a focus group

And your parent did not have surgery or die in an intensive care, or in the emergency room…

I would like to talk with you about the hospital care your parent received near the end of life. I am a nurse practitioner in the city of London and a graduate student in the Faculty of Nursing at the University of Alberta. I am dedicated to quality end-of-life care.

If you are interested in taking part in this study or if you would like to ask questions, please call or email me, Jacqueline Crandall, at the number below.

Appendix D

UNIVERSITY OF ALBERTA

FACULTY OF NURSING

Letter of Information

Study Title: Adult children's perceptions of the hospital care received by their advanced-age parents at the end-of-life: A sequential mixed methods approach.

Research Investigator:	**Supervisor:**
Jacqueline Crandall PhD Nursing Student University of Alberta	Professor Donna Wilson Faculty of Nursing, University of Alberta Edmonton, AB, T6G 1C9

Dear Participant:

Thank you for your interest in this study. You are being asked to be in this study because you have experienced the death of an advanced-age parent. Talking to family members who have experienced a loved one's death in hospital can help us understand how to improve care.

The aim of the study is to explore adult children's perceptions in relation to the end-of-life hospital care received by their parent. The purpose is to develop a theory of high quality end-of-life care for this population. The results of the study will be used in support of my PhD dissertation.

Study Procedures:

After completing a short 5 minute questionnaire about you and your parent, you will be asked to share your experiences of the hospital care provided during your parent's illness and death. There will be one or two interviews. Interviews will last about 60 to 90 minutes and will be arranged at a time and place suitable to you. The interviews can also be done on the phone. The topic of the interview will relate to your experience of the care provided to your parent during his/her illness and death in hospital. Our talk will be recorded using a digital recorder. A focus group may also be held near the end of the study for the purpose of ensuring completeness of the developing theory.

Risks of the Study:

I do not expect that you will be harmed by being in this study. During the interview, you may experience emotions that are upsetting to you. If this occurs, I will assist you and talk with you about obtaining support through local services. I will leave you a list of telephone numbers that you can call for additional support.

Benefits of the Study:

By being in this study, you will be helping to increase knowledge about the experience of end-of-life hospital care received by older adults. These results may help to improve care for older adults who die in hospital as well as their families. As a thank you for your time, you will be invited to a presentation that highlights the results of the study.

Confidentiality:

The results of the study will be written in the thesis and presented in publications and presentations. During the study, we will be collecting data about you and your parent. We will do everything we can to make sure that this data is kept private. No data relating to this study that includes your name will be released outside of the researcher’s office or published by the researchers.

Sometimes by law, we may have to release your information with your name so we cannot guarantee absolute privacy. However, we will make every legal effort to make sure that your information is kept private.

Digital recordings and electronic transcripts will be stored and accessed within the University of Alberta Health Research Data Repository, a secure virtual research environment developed to support health based research. Any paper transcripts, and other information collected from you in paper format will be kept in a locked cabinet. Signed consent forms will also be kept securely locked in a file cabinet to which only I will have access to. At the end of the study, the typed copies and digital recordings will be kept for a minimum of five years and will then be destroyed.

Voluntary Participation:

Being in this study is your choice. If you decide to be in the study, you can change your mind and stop being in the study at any time.

Further Questions:

If you have any questions about the research now or later, please contact Jacqueline Crandall at __________________.

If you have questions regarding your rights as a research participant, you may contact the Research Ethics Office at the University of Alberta at 780-492-2615. Collect calls are accepted.

Should you require immediate counselling, please call the crisis line at 1-866-933-2023.

Thank you for sharing your experience. Your comments and opinions are valuable. Please do not hesitate to call me.

Sincerely,

Jacqueline Crandall, RN (EC), M.Sc.N.
University of Alberta, Faculty of Nursing

Appendix E

UNIVERSITY OF
ALBERTA

FACULTY OF NURSING

CONSENT FORM

Title of Study: Adult children's perceptions of the hospital care received by their advanced-age parents at the end-of-life: A sequential mixed methods approach.

Principle Investigator: Jacqueline Crandall
Contact Number:

	Yes	No
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached information sheet?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to leave the study at any time?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to your records?	☐	☐
Do you want the investigator(s) to inform your family doctor that you are participating in this research study? If so, please give his/her name.	☐	☐
Name of doctor: ______________________________		
Who explained this study to you?		

The researcher may contact me for a further interview : ☐ ☐

I agree to take part in this study: ☐ ☐

Signature of Research Participant:
____

Printed Name:
____

Date: ______________________________________

Signature of Witness:
____
(Required if participant unable to read the consent for him/herself.)
I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee: Date:

Appendix F

Demographic Information

Participant Code: ___________

Please complete the following information by circling or filling in the blanks.

PARTICIPANT INFORMATION:

1. What is your present age: __________________

2. Your Gender: Male; Female; (Please circle)

3. What is the highest level of education you completed: (Please circle)

  a. Completed elementary school (Grade 8)
  b. Completed high school (Grade 12/13)
  c. Secondary school diploma/Trade school
  d. Undergraduate University degree
  e. Graduate degree
  f. None of the above
  g. Other: ___________

4. What is your present marital status? (Please circle)

  a. Single
  b. Married/partnered
  c. Separated/Divorced
  d. Widowed

5. What is your present occupation: __________________________

6. How many hours do you work outside the home? (Please circle)

  a. Less than 8
  b. 9 – 24 hours
  c. 24 – 40 hours
  d. Over 40 hours.

7. How many children do you have: _____________________;
  a. How many live at home? ______________________

  b. What are their ages?
    i. Under 5
    ii. 6 – 12
    iii. 13 – 18

   - iv. 19 – 25
   - v. Over 25

8. Are there others whom you care for now?

- a. Yes (explain): ___________________________________
- b. No

9. With whom did you share your parent's care?

- a. My parent's spouse
- b. My siblings (how many? _______________)
- c. No one else, I was the sole caregiver
- d. Other: ____

PARENT INFORMATION :

10. What was the age of your parent who died? ________________years old.

11. What was your parents' gender?

a. Male;   b. Female

12. What was your parent's marital status?

- a. Single
- b. Married/Partnered/Common-law
- c. Divorced/Separated
- d. Widowed

13. Where did your parent live prior to his/her most recent admission to hospital?

- a. Own Home
- b. Nursing Home
- c. Retirement Home
- d. Assisted Living
- e. With family member
- f. Other: _____________________________________

14. What illnesses did your parent have? (Circle all that apply).

- a. Cancer
- b. Congestive Heart Failure
- c. Chronic Obstructive Lung Disease
- d. Lung problems
- e. Stroke
- f. Severe Infection

g. Other: (explain): ____________________________________
h. I don't know

15. What was your parent's level of independence two weeks prior to hospitalization?

a. Totally Independent (able to own shopping, banking; cooking, managed own affairs; able to bath and dress on own without help).

b. Mostly Independent (required only minor help with driving, shopping, or banking; able to bath and dress on own without help).

c. Somewhat Independent (required help with shopping, cooking, and/or banking; able to manage bathing and dressing on own without help).

d. Mostly Dependent on others for shopping, cooking, and/or banking, AND required help with bathing and/or dressing.

16. What type of hospital was your parent last admitted?

a. Community hospital of less than 100 beds [Examples: ________________]
b. Community hospital of more than 100 beds [Examples: ________________]
c. Teaching hospital [Examples: ___________________]
d. I don't know. My parent died at:
____
(Name of hospital).

17. How long was your parent in hospital during the last admission?

a. Less than 1 week.
b. 1 – 2 weeks
c. 3 – 4 weeks
d. 1 – 2 months
e. Three months or more

18. What was the date of your parent's death?

Month: ____________, Year: ________________

19. How would you rate the overall hospital care received by your parent at the end of his/her life? (Please circle below)

0 1 2 3 4 5 6 7 8 9 10

Extremely poor
Worst ever

Outstanding
couldn't be better

Thank you for providing this information. Your input is highly valued.

Appendix G

Interview Protocol

Participant Code: _______________ Date/time: ______________________

Length: __________

Thank you for allowing me to interview you.

As you are aware, the purpose of this interview gain a greater understanding of your perceptions of the hospital care provided to your parent during his/her illness and death in hospital. My goal is to develop a theory of high quality end-of-life care for hospitalized advanced-age adults. The interview will take about 60 to 90 minutes. As discussed previously, I will be recording the interview and keeping it in a secure place. Your information will be kept confidential; only my supervisor, the person typing the interview, and I will have access to it. Please know that your participation is voluntary, and you can choose to withdraw at any time or choose not to answer particular questions. Do you consent to me recording this information?

Do you have any questions before we start?

Research Question:

- What do adult children of parents aged 85 and older consider as high quality hospital care for their parent when their parent's non-surgical admission to hospital ends in death?
  - What were the most significant events associated with the EOL care experienced?
  - How did adult children perceive the provision of EOL care?
  - What helped or hindered the provision high quality EOL care?
  - What were the outcomes of the quality of EOL experienced for the adult child, parent, and other family members?

---

1. I wonder if we can start talking, first, about you.
   Please tell me about you, your occupation, your family,
2. Please tell me about your parent.
   Age, personality,
   Illness
3. Please tell me about his/her last hospitalization.
   What was happening when your parent was admitted to hospital?
   How did you come to be involved? What was your role?
4. Please describe your experience in relation to the hospital care recieved by your parent.
   What happened?

   What else do you remember about the event?

5. What stands out about the hospital care received?

   Tell me about the most important thing that happened
   What happened that had the opposite emotional response
   When did you find out that your parent was likely not going to survive?
   What helped the situation? How so?
   What hindered the situation, or made it worse? How?
6. What was your experience of care around your parent's death?
   At what point where you aware that your parent was dying?
   What happened?
   How did that affect you?
   How did that affect others around you?
   What helped/hindered the situation?

7. Think about your background, for example, your culture, age, past experiences. How does your background influence your perceptions of the quality of end-of-life care received by your parent in hospital?

8. Now that you have had this experience, how would you define high quality EOL care?

9. What do you think are the most important ways for hospitals to promote quality EOL care?

10. Overall, how would you rate the EOL hospital your parent received during his/her last hospitalization?

11. If you could change anything, what would it be and how would that change your experience?

12. After having this experience, what advice would you give to hospitals? To other families?

13. We have reached the end of the interview. Is there something else that you may not have thought about that has occurred to you during this interview?

14. Is there something else you think important that I should understand?

15. Do you have any questions for me?

Thank you, once again, for allowing me to interview you.

May I contact you for a second interview? Yes No (Circle).

May I contact you to participate in a focus group? Yes No (Circle)

Should you wish to speak to someone about your feelings of grief, I have several resources to share with you.

In addition, if you have any questions in the meantime, you can call me anytime.

Interviewer: ______________________________

Appendix H

Receiving High-Quality of Care at the End of Life – Helpful Tips for Clinicians

Sub-themes	**Helpful Tips for Clinicians**	**Consequences for Adult Children**
Being Kept Informed	• Providing prompt information re: parent's condition in ER and early in admission (e.g. having scheduled times to meet). • Giving honest, clear information about illness, test results, and prognosis. • Having timely family meetings and assisting the transition to EOL care. • Helping to reframe realities of illness. • Providing options for care and support with decision making. • Knowing the patient and plan of care. • Keeping family up-to-date with parent's progress; informing family of room changes. • Informing family when condition changes or when death is near. • Providing information about the dying process (Stages of Dying). • Informing family of the quality of death when family not present.	• Increased understanding of nature of illness. • Increased awareness of approaching end of life. • Able to advocate for fewer tests and procedures. • Able to plan for parent. • Able to carry out parent's wishes. • Able to spend quality time with parent/family. • Able to plan for home death if desired.
Receiving Care with Compassion	• Connecting with family by showing care and empathy; Asking, "How are you?" • Involving family in establishing plan/goals of care. • Sitting down, listening, and asking, "What is important to you and your parent?" • Being attentive to parent's needs. • Guiding families through unfamiliar territory. • Providing support and reassurance to family while meeting parent's needs. • Acting as parent/family advocate.	• Being heard & cared about. • Being supported. • Being acknowledged. • Being given validation regarding how difficult situation must be. • Being reassured that staff are caring for parent in the best way possible.
Receiving Optimal Care & Comfort	• Providing good physical care (e.g. hygiene, mouth care, repositioning). • Being perceptive to needs; checking in every hour. • Having an appropriate diet arranged. • Ensuring comfort (e.g. pain control, warm blankets).	• Being reassured parent is given good care and kept comfortable. • Not stressing and worrying about care; Family can focus on things that matter to parent.

	• Providing a comfortable environment (tidy room, clean bed). • Ensuring a coordinated plan of care is in place (e.g. communicating plan of care between units, facilities; involving & informing family). • Recognizing when patient is nearing end of life. • Facilitating referrals to hospice palliative care. • Providing family with comfortable environment (e.g. chairs, cots, blankets).	• Increased trust and confidence in the healthcare system. • Family able to leave parent's room and feel assured that parent will be well cared for. • Having a space to be with family.
Being Treated with Respect and Dignity	• Acknowledging patient as person, using his/her name. • Recognizing cognitive abilities (baseline), communicate accordingly. • Recognizing delirium. • Not treating parent as a 'child' or 'old man or woman.' • Acknowledging the role of family in developing plan of care. • Being mindful of verbal & body language. • Providing family balanced privacy. • Providing respectful care at time of death, (e.g. positioning of decendent's body, involvement of family). • Allowing time for family to be with parent after death.	• Knowing parent was honoured and treated as an individual. • Feeling valued, acknowledged, and supported.