BEREAVED FAMILY MEMBERS' AND HOSPICE NURSES' PERSPECTIVES OF

TRANSITIONS TO AND BETWEEN RESIDENTIAL FACILITIES

FOR THE DYING ELDERLY

by

Camille (Kim) Martz

A dissertation submitted to the faculty of
The University of Utah
in partial fulfillment of the requirements for the degree of

Doctor of Philosophy

College of Nursing

The University of Utah

December 2014

The University of Utah Graduate School

STATEMENT OF DISSERTATION APPROVAL

The dissertation of   **Camille (Kim) Martz**

has been approved by the following supervisory committee members:

Janice Morse	, Chair	**7-23-14**	Date Approved
Lee Ellington	, Member	**7-23-14**	Date Approved
Ann Hutton	, Member	**7-23-14**	Date Approved
Janet Reis	, Member	**7-23-14**	Date Approved
Sharon Stephen	, Member	**7-23-14**	Date Approved

and by   **Rcvtlekc'I 0O qtton**   , Chair/Dean of

the Department/College/School of   **Nursing**

and by David B. Kieda, Dean of The Graduate School.

ABSTRACT

Care transitions for elderly family members enrolled in hospice care to and between home, Assisted Living Facilities (ALF), and Nursing Homes (NH) are fraught with distressing emotions and suffering for both the elderly persons and their families. The purpose of this study was to explore how bereaved families, after the death of their loved one, experienced and perceived these care transitions. Hospice nurses also participated in the study, to provide their perceptions of the end-of-life transition.

Glaserian grounded theory (GT) was used to systematically generate theory from the data. Thirty-nine unstructured interviews were conducted with family members (*n*=14), hospice nurses (*n*=13), an ALF nurse (*n*=1), and social workers (*n*=2). Additional interviews were conducted with family and hospice nurses (*n*=5) and theoretical group interviews were also conducted (*n*=4). Data were coded using interpretive, axial, and selective coding. Analysis commenced concurrently utilizing GT principles of constant comparative method as well as memoing. A theoretical model was developed of the stages of the basic social psychological process of *Living Through Care Transitions of the Dying Elderly: The Changing Nature of Guilt in Family Caregivers*. Findings indicated that guilt escalated during the initial stages of the transfer, and was mitigated by achieving what family members deemed as a "good" death.

The experiences and perceptions of the hospice nurses were identified during each phase of the care transition. Results revealed the hospice nurses role in *alleviating guilt*

for the family caregivers was by *supporting the transition* through *advocating*, *navigating* the complexities of both facility systems and families, and especially *coaching* during the dying process, which was seen as the critical support for families during that stage.

The findings provided new insight into the nature of guilt and its resolution in bereavement through the attributes of a "good" death. If a "good" death was not achieved, guilt appeared to linger; however, this needs further study. Furthermore, findings also provided educational stage-specific implications for hospice nurses supporting family caregiving through difficult care transitions. Implications of this research also highlight significant issues that affect families caring for older adults that can influence public policy.

This dissertation is dedicated to my family. To my husband, Harry, for his unwavering support, my son, Joshua, who encouraged me to continue my education, and to my daughter, Erica, who listened and coached and was a source of wisdom beyond her years. To my Dad, Harold, who was my biggest fan. He has passed but is watching over me and I know he would be extremely proud. And to my Mom, Julia, age 94, who transitioned to a nursing home in the remaining few weeks before my defense, which demonstrated to me the importance of my findings. It broke all of our hearts and reiterated the need to better understand these processes. Also, to my in-laws, Harry and Alma Martz, for their encouragement and support.

.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

ACKNOWLEDGEMENTS

CHAPTER 1

INTRODUCTION

Family caregivers of the dying elderly are especially vulnerable during the

distressing time of care transitions from their residence to Assisted Living Facilities

(ALF), and/or Nursing Homes (NH).   Very little is known about these care transitions,

especially for those older adults enrolled in hospice care. Initially, this study was

intended to focus entirely on the care transitions that occurred from ALF to NH for those

elderly who were enrolled in hospice care. However, Glaserian grounded theory is that

of an inductive approach in which "discovery" is one of the central tenants (Glaser,

1968, 1998); therefore, during the initial data collection phase, the problems of care

transitions from the family residences to ALF and NHs were also revealed to be

problematic so that the definition of "home" expanded accordingly.   Therefore, the

literature review (Chapter 2, Background and Significance) was updated to include issues

of end-stage family caregiving to NH, as well as ALF to NH placement. The methods

used in the study are fully described in Chapter 3. The findings of the study are presented

as articles in Chapter 4 and 5: Chapter 4, *Living Through Care Transitions of the Dying*

Elderly: The Changing Nature of Guilt in Family Caregivers, and Chapter 5, *Actions of*

Hospice Nurses to Alleviate Family Caregivers Guilt during Care Transitions for the

Dying Elderly. In Chapter 6, the study is discussed and the implications for further

research, education, and policy are presented.

<div align="center">Statement of the Problem</div>

The number of older adults with chronic conditions and disabilities requiring

assistance with daily living care is increasing annually. The majority of frail older adults

do not live in a nursing home but receive assistance largely from family, principally

spouses and adult children (Johnson & Weiner, 2006). According to *A Profile of Frail

Older Americans and Their Caregivers*, in 2002, 8.7 million people age 65 and older

were living at home and 61.3% of those not residing in nursing homes rely on family for

help (Johnson & Wiener, 2006).   Older adults prefer to remain in their own homes and

die at home; however, as the aging population with chronic conditions are living longer

and longer, the time span for assistance from family is ever-increasing as well. The last

year of an older adult's life may often result in increasing care needs due to multiple

medical problems (Kaspers, Pasman, Onwuteaka-Philipsen, & Deeg, 2013). Often

hospice care provided in the home can assist in accommodating end-of-life care;

however, along with eligibility requirements, there are physical, emotional, and financial

issues that necessitate a care transition to residential or intuitional care. Care transitions,

especially to nursing homes, have been known to be a life crisis for patients and their

families and have been well studied (Dellasega & Mastrian, 1995; Kellet, 1999; Penrod

& Dellasega, 2001; Ryan 2002; Strang, Koop, Dupuis-Blanchard, Nordstrom, &

Thompson 2006).   The place of care during this last phase of life is of interest especially

since older adults prefer to die at home and family members will continue to shoulder

most of the burden for care (Kaspers et al., 2013).

The care of dependent older adults, traditionally cared for by family members, is shifting due to a variety of circumstances impacting United States (US) families. Along with geographical distances of family members, economic pressures and cultural shifts lead to more women or adult daughters working outside the home, who traditionally have provided the care for aging parents (Johnson & Weiner, 2006; Waldrop & Meeker, 2011). Thereby, the needs for formal caregiving and the need for alternative housing arrangements are increasing dramatically (Kelsey, Laditka, & Laditka, 2008).

Cultural changes and the complexities of an aging society have resulted in the growth in residential care/assisted living facilities (ALFs) as an alternative to nursing home placement for elders (Cartwright & Kayser-Jones, 2003). Although residents desire to age and die in their ALF "home," it is challenging for staff to provide high-quality care experiences, especially at the end of life (EOL) (Cartwright & Kayser-Jones, 2003).

Despite the need and intention of the elderly to "die in place," only 26% of residents actually die in their ALF. Most residents discharged from ALFs (i.e., 25% to 45%) are transitioned to a nursing home. Some are transferred directly to the hospital. This rate of hospitalization for ALF residents is higher than for community-dwelling elderly, but reasons for the transfers are unknown (Mitty, 2004). While residents and their families support aging and dying in place in their assisted living "home," policies and processes are necessary to meet EOL care needs (Cartwright, Hickman, Perrin, & Tilden, 2006).

One barrier to aging in place and thereby *dying in place* includes state regulations and agency policies. While each state has its own requirements, staffing of Registered

Nurses (RNs) or Licensed Practical Nurses (LPNs) varies in ALFs, and few states require that staff include a director of nursing or medical director (Mitty, 2004). Medication management is also regulated by each state's definition of "assistance" with medication and may require a trained assistant to monitor medication. Trained assistants are not licensed to assess patients who may require additional pain medications as needed at the EOL. Liability due to the unavailability of licensed nursing around the clock may cause a dying resident to be transferred to a nursing home or hospital unless the resident is enrolled in hospice care. Even with hospice coverage, there is still a risk of being transferred due to lack of staffing and the prohibitive cost of increasing services (Mitty, 2004). Continuity of care may be lost with this transition to a new environment.

Hospice Care

According to the National Hospice and Palliative Care Organization (NHPCO), the majority of the 1.6 million hospice patients receive care in the place the patient calls "home" (2013). NHPCO included caregivers in their research agenda recognizing the need to examine the family caregiver experience (NHPCO, 2004). In addition, the World Health Organization (WHO) advocates for health services that include families in improving their quality of life and assist families with coping from caregiving through bereavement (Hudson & Payne, 2011). The literature is sparse concerning the crisis of transitioning elderly hospice patients from their home to ALF or NH and the majority focuses on transitions to inpatient hospice facilities (Eagle & de Vries, 2005; Evans, Cutson, Steinhauser, & Tulsky, 2006; Hurley, Strumpf, Barg, & Erserk, 2014; Waldrop & Meeker, 2011)

Very little is known about the experiences of ALF hospice patients who are transferred to a hospital when dying is imminent (Mezey, Dubler, Mitty, & Brody, 2002). Some facilities consider hospice support as the critical factor in providing the complex care needed at the EOL for residents to stay and die in their ALF (Cartwright, Miller, & Volpin, 2009). Although most ALFs offer hospice care, little has been reported about hospice usage in ALFs. Only a few studies have examined the regulations regarding delegation from the hospice nurse to the ALF staff, and those studies reported difficulties with communication and coordination of care (Cartwright et al., 2009; Mezey et al., 2002).

Health Care Transitions

Health care transitions may be defined as hospital discharge or the transfer from one health care setting to another (Geary & Schumacher, 2012). Older adults are particularly vulnerable during these transitions due to the discontinuity of care. To provide an optimal dying experience, residents are referred to hospice. Yet this transition in care may not prevent them from transferring to another setting at the EOL. The Institute of Medicine (IOM) recommends that care should be based on continuous healing relationships with health care professionals; however, during transitions, these relationships are at risk of termination or replacement (Geary & Schumacher, 2012). While much attention has been directed at empirical research in this area due to the overwhelming costs of hospital readmissions, virtually no studies have examined the families' or hospice nurses' perspectives on the impact of transitions from home to ALFs or NH, as well as multiple transitions at the EOL.

The setting where people die has an impact on the quality of life that older adults experience and also influences the quality of death (Mezey et al., 2002). Consequently, the transition itself may affect the quality of the dying experience (Mitty & Flores, 2008; Mollica & Jenkens, 2001) and the experience witnessed by families of a "good death." The attributes of a good death are highly individualized, changeable over time, and based on perspective and experience (Kehl, 2006). The Institute of Medicine (IOM) also claimed that a "decent or good death is 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" (IOM, 1997a, p. 3). The location of a person's death is an important component, and "home" is the preferred location (Gruneir et al., 2007). When a person is transferred to another care facility at the EOL, the patient and family need to navigate a new system along with relationships with new health professionals during a highly stressful time.

According to Teno et al. (2004), many people dying in institutions have unmet needs and concerns with the quality of care at the EOL, especially those dying in hospitals or nursing homes. Families report issues of unmet needs of pain management, dyspnea, as well as emotional support and whether the patient was treated with respect. The families' perceptions of quality of care differed by the last place of care (Teno et al., 2004), although ALFs were not included in that study. Transitions from home to ALFs or to NH settings at the EOL may have a profound impact on these families and on the quality of dying for older adults (Mezey et al., 2002). Yet no studies have evaluated family perceptions of care during these transitions. However, transferring to another setting of care has shown to have burdensome consequences of stress, depression,

financial burden, loss of personal possessions, and loss of personhood (Mitty & Flores, 2008; Mollica & Jenkens, 2001) Unfortunately, such transitions in the last months of life are common, vary according to state, and are correlated with poor quality in EOL care (Gozalo et al., 2011). Patient- and family-centered outcomes of care are central to developing quality care models. Families and other informal caregivers are crucial to the care and coordination of health providers, as well as the emotional support of these older adults in ALFs during these years.

In summary, many issues face older adults in health care and where they reside until the end of life regardless of their preferences. Adults 85 years and older are the fastest growing population in the United States; of those over 85 years old, 40% die in nursing homes and other long-term care facilities (Span, 2012). There is no evidence that suggests that those deaths were actual residents of the nursing homes. According to Gozalo et al. (2011), site-of-death data only tell where one was at time of death and nothing about the transitions that lead to that point. Almost one in five experiences a burdensome transition in their final days, which includes multiple hospitalizations or moves from nursing homes to hospital (Gozalo et al., 2011).   There is a paucity of studies surrounding care transitions for hospice patients, and these transitions are primarily to an inpatient hospice setting and do not all include the dying elderly. What challenges do these transitions present for residents and their families at this difficult time? Studies have not examined the impact of these experiences or the perception of families of ALF residents, although studies have indicated that having security and trust in the health care professionals, such as those of the hospice care providers, was found to be of great importance (Andershed, 2006). Very little is known about transitions that

occur for older adults residing in their homes or ALFs to Skilled Nursing Facilities/Nursing Homes who are enrolled in hospice.

<div align="center">Purpose</div>

The purpose of this study is to explore the circumstances and interpret the impact on families' and hospice nurses' perceptions and experiences of care transitions to and between residential care facilities, such as ALFs or NHs, at the EOL for older adults who were enrolled in hospice. This qualitative interpretation of families' and hospice nurses' perceptions and experiences led to the development of a situation-specific model of the transitions in care at the EOL.

Because research from a family-focused perspective is limited in the AL setting, those experiencing care transitions from home, and also in hospice family caregivers, interviews with bereaved family members enabled me to gain some understanding of the challenges faced by families and how they perceived the care of their family member at the EOL. Hospice nurses also offer a unique perspective of the difficulties in providing care during these transitions. Capturing the stories of families and hospice nurses who had actual experiences in the home setting as well as with these residential care facilities offered greater understanding of the quality of the care being received at the EOL. It provided an opportunity for educational implications for hospice providers and also an opportunity to advocate for policies that would support models of care to assist older adults to age and die in their "home."

Specific Aims

Aim 1: To identify and explore the experiences and perceptions of families regarding care transitions of their dying elderly.

RQ: How is the family affected by the care transfer of the dying elderly from their home or ALF to nursing home?

Aim 2: To identify and explore hospice nurses' experiences and perceptions of caring for the patient and their family during care transitions to and between home, ALF facilities, and nursing homes at the EOL.

RQ: What are the perceptions and experiences of hospice nurses regarding families' needs during transitions of their dying elderly?

<div align="center">Summary</div>

Providing care to elderly relatives is becoming increasingly recognized as a critical issue because of changes in health care systems, as well as an ever-increasing aging population (Kita & Keiichi, 2011; Penrod & Dellesaga, 2001). Uncovering the salient issues through qualitative research will provide a stronger understanding of patient and family's needs during these care transitions and facilitate the development of stage-specific interventions for hospice nurses to support families. In this research project, I identified a trajectory that provided insight into families' and the hospice nurses' perceptions of the quality of EOL care that involves a transition from either their home or an ALF to a nursing home for those in hospice care. This theory provided a critical appreciation of the care needs of patients and their families and a basis for further study that have implications for nursing practice and health care policy.

In Chapter 2, the literature review presents my findings of the current state of the science of EOL care in residential care, including ALF and Nursing Homes/Skilled Nursing Facilities (NH/SNF) as well as of families' perceptions of care. Also, the literature on transitions provided a foundation for understanding the concepts related to the current study. As part of the iterative nature of grounded theory inquiry, this literature was continuously reviewed and updated based on the findings.

CHAPTER 2

BACKGROUND AND SIGNIFICANCE

The specific aims posited for this study included the following primary areas of
literature: assisted living facilities (ALFs), Skilled Nursing Facility/Nursing Home
placement, hospice, EOL care in ALFs, family perceptions of care, end-stage family
caregiving, and transitions. The literature available on assisted living, specifically EOL
care in ALFs, was limited; therefore, literature from analogous settings was examined to
provide a synopsis of the pertinent issues related to this study.

The purpose of this literature review was initially to examine concepts related
specifically to the ALF environment; issues involving aging and dying in place
(specifically hospice care in ALFs); however, family caregiving and perceptions at the
end of life as well as nursing home placement were included to update the literature
review based on the evolution of the study. Also, the research on transitions at the EOL
was examined, as well as theoretical concepts related to transitions. Search strategies
included databases such as: PubMed, CINAHL, MEDLINE, Ageline, Scopus, and
Google Scholar. In addition, searches using specific authors relevant to this research area
were used. The search was of primary sources limited to English language and mostly
U.S. studies, due to national difference in the regulations in long-term care and ALFs.
Because ALFs are relatively new housing options for seniors, the inclusion dates are
1989-2012; however, as the study developed to include nursing home placement, the

inclusion dates expanded from 1980-2014. Initial relevant literature is presented in Appendix A. In this review, I presented an overview of assisted living and analyzed the empirical results related to aging and dying in place, including hospice in ALF. I also reviewed family perceptions of care at the EOL in nursing homes and ALFs as well as the literature on nursing home placement of the elderly. The concept of care transitions were examined for both empirical and theoretical data. A summary of the major findings concludes the review, and illuminated the need for further research.

Overview of Assisted Living Facilities

Assisted living (AL) can be seen as a reaction in the early 1980s against the nursing homes that had become common in the United States for older adult long-term care. The perceptions of low standards of care and lack of patient autonomy in nursing homes influenced the development of different models of assisted living facilities (ALFs) in response to consumer and socioeconomic forces in the older adult population. Currently, more than 733,400 older adults reside in assisted living or residential care facilities (Centers for Disease Control and Prevention [CDC], 2010). ALFs offer help with activities of daily living and combine housing, health care, and support services as needed (Assisted Living Federation of America [ALFA], 2001) for the older adult. Although there is not a consistent definition of "assisted living" across the country, most states use the term "assisted living" to license these facilities. The philosophy of care emphasizes privacy and greater control and choice over eating, sleeping, and bathing than what is available in a nursing home setting. Most people believe "assisted living" to mean that residents have choice, autonomy, privacy, and dignity just as they would have if they were aging in their own homes (Mollica, 2008). This philosophy of maximizing

independence and accommodating residents' changing needs includes promotion of the ability to "age in place" (Ball et al., 2004).

Most residents in ALFs (91%) are non-Hispanic Whites, females (70%), and aged 85 and over (54%). The average length of stay among all residents is about 22 months (Caffrey et al., 2012). The most recent estimates reported that 38% of residents receive assistance with three or more activities of daily living, and almost half (42%) have Alzheimer disease or other dementias (CDC, 2010). Because Medicare is not likely to cover services in AL settings and Medicaid only pays for a small percentage of residents in certain Medicaid facilities, a national definition and national operating standards for ALFs are not provided by the federal government. Most residents (88% to 90%) are private payers, and most ALFs are regulated by state governments.

In most states, admission criteria require that the resident does not need 24-hour supervision or nursing care. Most define this type of care as anyone not needing a feeding tube, ventilator, or wound care. Currently, 10 states prohibit admitting anyone or continuing care for anyone with a stage III or IV pressure ulcer (Zimmerman, Sloane, & Eckert, 2001). However, different states use different approaches. Some states may grant waivers that allow facilities to serve residents whose needs have exceeded the state requirements, such as in EOL care (Mollica, 2008). These waivers allow facilities to forego discharge criteria if the residents can secure additional services to meet their needs (Mitty & Flores, 2004). In addition, some facilities implement a negotiated risk agreement (NRA) at the beginning of a resident's stay to assist in individualizing care while at the same time allowing residents to acknowledge the risks that may be involved in choosing an ALF. These NRAs also are a means to ensure the ALF's responsibility to

notify the family if the resident's condition changes (Mitty & Flores, 2004). Idaho

regulations allow waivers; however, they do not monitor the creation or use of NRAs.

In the state of Idaho, assisted living facilities are defined as follows:

> Residential Care or Assisted Living Facilities for the elderly/seniors include any
> facility or residence, however named, operated on either a profit or non-profit
> basis for the purpose of providing necessary supervision, personal assistance,
> meals and lodging to three or more elderly adults not related to the owner…
> (Idaho Department of Health and Welfare, 2012)

There are 286 licensed facilities in Idaho. Of these facilities, the residents'

demographics include 51% elderly (65 and over), 30% Alzheimer/dementia, 11% mental

Illness, 4% developmental disabilities, 3% physical disability, and 1% traumatic brain

injury (Idaho Department of Health and Welfare, 2012).

The Idaho Residential Care or Assisted Living Act states that an ALF may not

admit or retain any resident requiring a level of services or a type of service for which the

facility is not licensed or which the facility does not provide or arrange for, or if the

facility does not have the staff, appropriate in numbers with the appropriate skills to

provide (State of Idaho Legislative, 2012).

Review of the Research Conducted in Assisted Living

The assisted living environment is a relatively new research area. Since the first

AL environment emerged 31 years ago, there has been an ever-increasing amount of

research from a variety of disciplines, yet this area is still underexplored. Kane, Chan,

and Kane (2007) conducted a literature review of AL from 1989 to May 2004 and found

qualitative studies to be prevalent and necessary to develop the most salient constructs.

Most studies (120) were performed using primary or secondary data collection (Volpin,

2011). The authors indicted there was little standardization for measuring variables and better reporting was needed on sampling, time frames, and measures (Kane et al., 2007).

Gaugler and Kane (2007) conducted a literature review of families and ALFs and found 62 appropriate manuscripts for inclusion. Study subjects ranged from family structures in AL and family involvement in AL to family-related outcomes. Of these studies, none addressed EOL care. Only four studies in the literature on aging in place in ALFs addressed EOL care (Ball et al., 2004; Degenholtz, Rhee, & Arnold, 2004; Zimmerman et al., 2003), and there were only four studies on hospice in ALFs (Cartwright & Kayser-Jones, 2003; Cartwright et al., 2009; Dixon, Fortner, & Travis, 2002; Munn, Hanson, Zimmerman, Sloane, & Mitchell, 2006; Appendix B).

Three of the four studies on hospice in ALFs had very small sample sizes including family members (*n=4*, *n=4*, and *n=6*). The largest study was conducted in both long-term care and ALF. Two of the studies that specifically included hospice in their samples described the difficulties with communication and coordination of care in ALFs (Cartwright et al., 2009, Dixon, Fortner, & Travis, 2002).

Aging and Dying in Place

The CDC defines *aging in place* as "the ability to live in one's own home and community safely, independently and comfortably regardless of age, income, or ability level" (CDC, 2013). Although older persons prefer to age in place at their own home, this concept has been extended to ALFs, where the environment is less restrictive than a nursing home (Ball et al., 2004). To embrace and successfully age in place means that a resident could eventually die in place; however, earlier studies demonstrated that dying in

place was not always possible (Chapin & Dobbs-Kepper, 2001; Hawes, Phillips, Rose, Holan, & Sherman, 2003).

Wilson (2007) undertook a historical analysis of assisted living facilities from 1979 to 2000. Aging in place was originally part of the vision of assisted living, and residents were not required to relocate if they needed more care. Consumers and their families were attracted to ALFs due to the ability to choose relocation to a more care-oriented facility if it became necessary (Wilson, 2007). Wilson suggested that rigorous research surrounding the original values and key concepts that were the foundation for ALFs may provide a mechanism to suggest practice, regulatory, and payment models. Summarizing these concepts:

1. Normalized environments and homelike residential features.

2. Enhanced service capacity to foster residents' well-being.

   a. Responsibility for coordination of services (i.e., hospice) and oversight of transitional events such as move in and move out.

3. Values orientation to preserve residents' self-worth. (Wilson, 2007)

Research addressing aging and dying in place in ALFs is limited. Ball et al. (2004) is one of four studies of aging and dying in place and assisted living. These authors sought to gain an in-depth understanding of the factors influencing the ability of residents to remain in assisted living. Findings from that study's authors of a grounded theory investigating the process of aging in place in ALFs point to the complexity and need for a coordinated effort by facilities, residents, and families in the management of the resident's decline (Ball et al., 2004). That study's findings also highlighted the

importance of residents being well-informed about their own needs and the capacity of the facility to meet them.

Mitty (2004) described the regulatory and operational environment of AL in regards to managing the older adult residents' decline by providing upstream palliative care (UPC). UPC is care that is initiated when a chronic disease is first diagnosed and includes goals of care as established by the resident and family. The facilitators of UPC include advanced care planning, pain and symptom management, interdisciplinary team approach, quality of life, and staff education (Mitty, 2004). That research also examined ALF regulations and Nurse Practice Acts of 22 states and surveyed stakeholders such as regulators, nursing boards, and professional nursing and palliative care association members for their perceptions and experience regarding UPC, aging in place, and EOL planning and care in ALFs. The key finding of that study was that stakeholders did not support dying in place as an outcome of aging in place in ALFs. This finding indicates a gap in care continuity and an area where nursing should have a significant voice and role in this continued discussion of managing decline, aging in place, and UPC. Research is needed to understand the impact of discontinuity on patients and their families.

Bernard, Zimmerman, and Eckart (2001) presented a conceptual model describing aging in place in ALFs in terms of person-environment fit and the need for the facility to continually assess in order to meet residents' changing needs. There are no studies currently in the literature evaluating the use of this conceptual model for fit or further extrapolation.

In a national study of assisted living, Hawes et al. (2003) reported a limitation in the ability of ALF residents to age in place. Those authors concluded that the answer

depends upon the interpretation of aging in place. It is uncertain if the resident's expectations of living in these facilities to the end of his or her life are well communicated to consumers. More than 67% of consumers were uninformed about facility policies on retention and discharge. This uncertainty is evident in that 98% of residents in the national study of ALFs believed that they would be able to stay in the ALF for as long as they wished. Hawes et al. (2003) also reported that approximately 24% of residents left the ALF and went to a nursing home (16%), while the remaining was hospitalized or had died. The most common reason for leaving was a need for more care.

Since ALF environments are relatively new to the long-term care continuum, research gaps are evident. Longitudinal studies will be necessary to better understanding the issues involved in the public's perceptions along with the actual reality of aging in place. The inevitable decline that older adult's face and the family expectations of viable alternatives to nursing homes are gaps in the current literature and demonstrate the need to begin to understand the salient issues involved for vulnerable older adults and their families. For one, the person-environment fit model has not been tested and may further define and address regulatory issues that prevent residents from remaining in the facility. However, prior to testing models, developing an understanding of the issues and challenges families and residents face when they are not able to remain in the facility at the end of life as well as the impact of hospice care may influence policies for supporting resident to remain in these settings over time. The science is relatively weak on the impact of transitions on residents and their families. With an ever-increasing demand for alternatives to care for older adults as well as the influx into these facilities, it becomes

imperative to understand how to meet the challenges of this growing aging population as well as develop an understanding of hospice's influence in facilitating aging and thereby dying in place.

<u>Definition and History of Hospice Care</u>

Hospice is an ancient concept that meant caring for a stranger who was traveling. The Sisters of Charity, a Catholic nursing order, in the 18th century founded places to care for the sick and the dying through creating homes called hospices. These Sisters of Charity hospice facilities influenced Florence Nightingale as she was transforming nursing to include this philosophy of care. The first modern hospice was established in 1905 by the Irish Sisters of Charity; the modern concept of the hospice philosophy is most notably associated with Dr. Cicely Saunders who opened her hospice in 1968 in England, following in name and tradition the Christian roots of the word (David, Konishi, & Mitoh, 2002).

According to Jennings (1997), there are three ethical and moral issues in hospice care: autonomy, palliation, and good dying. Since its inception, hospice has at its core personal dignity and respect for the dying person. It is strikingly different from the invasive life-support technologies that can be employed in acute care. Hospice affirms the autonomy of the patient to refuse life-sustaining treatment. In Jennings's book, *Ethics in Hospice Care: Challenges to Hospice Values in a Changing Health Care Environment,* he emphasizes that hospice even looks beyond palliation and autonomy to seek healing, which comes from the root meaning of "making whole" (1997, p. 4). This idea of good death is in his words about "sustaining relationships, sustaining the integrity

of the self, and achieving an appropriate closure to one's life through reconciliation with one's past, one's self-identity, and with others" (1997, p. 4).

The ultimate goal of the hospice mission is providing good quality EOL care. If patients and their families are transitioning to new environments of care during their final days, is hospice able to facilitate a good death? The empirical data about hospice in ALF is sparse, particularly from the family's perspective.

<u>Hospice Care in Assisted Living Facilities</u>

The coordinated effort to meet residents' needs to age and to die in place is often provided by hospice care. The National Center for Assisted Living (NCAL; 2010) reports that 65% of all ALFs allow hospice services. ALF administrators support hospice involvement when a resident is terminally ill (Dixon et al., 2002; Sloane et al., 2003). If the resident's medical and functional needs are beyond what a facility can manage to keep them safe, a nursing home or hospital is often considered. The NCAL 2000 survey reported that 33% of ALF residents were sent to a nursing facility (Caffrey et al., 2012). The ability to age in place is negated once the resident has a problem with safety, including frailty and death. If the resident's needs become more palliative with symptom management, the only option is to be placed in hospice care because then more services are provided. However, the admission and discharge requirements of the facility still influence whether the patient is safe enough to be able to stay in the ALF. Hospices can apply for a waiver that allows the resident to remain in the facility at the EOL. However, waivers are only for 30 days, and the resident may not die in that time.

Few studies have been conducted involving hospice and ALFs. A pilot study, The Collaborative Studies of Long-Term Care (CS-LTC), conducted in four states in

2000 found a hospice rate in ALFs of 27% (Munn et al., 2006). Cartwright and colleagues (2009) conducted a study of ALF residents enrolled in a hospice program by interviewing ALF staff and hospice RNs about their experiences of good EOL care. This study identified the quality of the relationships among resident, ALF staff, and other care providers as the critical component of providing good-quality EOL care (Cartwright et al., 2009). Although the family was not included in this study, the ALF staff and hospice RNs reported that strong teamwork, good communication, and use of multiple sources of knowledge, along with shared expectations about managing problems, contributed to accomplishing the resident's goal to die "at home" and in comfort (Cartwright et al., 2009).

Researchers concluded that dying in place was associated with living wills, which are a type of advance directive (Degenholtz et al., 2004). The advance directive used by hospice is a Physicians Orders for Scope of Life-Sustaining Treatment (POLST). These directives are put in place from the time the patient is enrolled in hospice care. The directives include do-not-resuscitate orders and other such preferences for comfort care. Having these documents in place is associated with a lower probability of dying in a hospital for community dwellers, as well as for nursing home residents (Degenholtz et al., 2004). Still, specific research has not been conducted on this subject in ALFs.

Transporting traditional hospice care that was originally designed to be delivered in a person's home environment to these institutional settings is fraught with barriers, challenges, and opportunities (Dixon et al., 2002). Families are the key to providing additional care at these times. Yet no research has explored families' involvement in care at the EOL in ALFs. They have, however, explored families' perspectives.

Family Perspectives of Care

The literature on family perspectives of care at the EOL encompasses EOL care for a variety of age groups, illnesses, and settings. Also the literature on families' perspectives of hospice care contains similar variables. The literature on family perspectives in AL settings is limited; therefore, much of this literature review will include research related to the nursing home setting. Although there are differences in the setting, it is the closest model of institutional long-term care. The main differences for families of AL residents is that the involvement and burden for the family is higher in an AL than in a nursing home setting because there is a higher level of professional carers in nursing homes (Port et al., 2005).

A systematic review of the literature from 1999-2004 focusing on relatives' situation and needs in EOL care (Andershed, 2006) primarily included descriptive/exploratory study designs. The term "relative" was used to depict the concept of family which can include caregiver, carers, or next of kin. Irrespective of the name given, the meaning was the same: one person as a voice for the family. This research demonstrated the multiple and complex needs of relatives and the changing needs of patients and relatives as the dying trajectory progresses. It is interesting to note that although 94 studies were included in this review, the author reported that, though "family" was one of the search words, no studies were found that were based on the family (Andershed, 2006). Andershed (2006) also reported that there was little evidence regarding difficulties arising during ethical dilemmas and the differing voices within one family leading to conflicts, which are crucial to understanding how these families cope and what interventions could be helpful. There were no studies identified in this review surrounding health care facility transitions at the EOL. The results were based on family

satisfaction of care and, consistent with Teno et al. (2001), again demonstrated that of greatest importance was the family's feelings of trust in the professional. This has grave importance for patients and families undergoing transitions during this critical time because they find themselves needing to develop new relationships with new health care providers while at the same time dealing with their feelings of grief in the face of the loss of their loved one.

Family members are an essential component of caring for a dying patient and should be considered a factor in the care. Although the patient will be gone, the family members will remember and replay the experiences of their loved one at the EOL (Marco, Buderer, & Thum, 2005). Very little is known about what constitutes family members in these settings. Family members may be spouses, adult children, siblings, grandchildren, or friends as proxy. Rich, Williams, and Zimmerman (2009) conducted a study in which 67% of respondents were adult children. This study evaluated concordance of family member and staff reports of EOL in assisted living facilities and nursing homes. Findings suggested that, as opposed to other types of family members, relatives who were adult children had perceptions that were most similar to those of staff members.

Gaugler and Kane (2007) examined family involvement in AL and found frequent visitations but a minimal amount of personal care was provided. Families indicated high satisfaction with the care in AL, but also the potential for care burden. The family care burden for AL was greater compared to nursing homes because of the increase in decline along with the financial burden for increasing care needs (Gaugler & Kane, 2007). That study was one of the only articles that synthesized quantitative and qualitative research

on family involvement. Gaugler and Kane (2007) concluded that there are conceptual limitations in family involvement research because the majority of the research was from the perspective of a *primary family member*, which is that person who feels most responsible for the relative. Further research is needed to examine other types of family configurations.

Family members are especially significant as caregivers in nursing homes and residential care/ALFs. Families help in making decisions regarding moves to these settings and also feel responsible for overseeing and advocating for their care (Bern-Klug & Forbes-Thompson, 2008). The decisions for caregiving are made jointly with facility staff or care teams. The decisions may become more complex at the EOL regarding the goals of care (Rich et al., 2009).

Kehl and colleagues (2009) examined challenges faced by family members at the EOL in three different care settings: inpatient hospice, skilled nursing facility, and a community support program. Two of 12 themes emerged in all three settings: bearing witness and the experience of loss. *Bearing witness* was identified as the act of observing the experience of the dying person without being able to affect the outcome (Kehl, Kirchhoff, Kramer, & Hovland-Scafe, 2009). It was reported that both caregivers and nurses bore witness to the decline and suffering at the EOL; caregivers reported difficulty, while it was viewed as a caring act by the nurses. Experiencing loss was also common in all settings. A variety of loss experiences were reported—from the loss of the caregiving role to the loss of companionship and sometimes the loss of the dying person not recognizing them anymore (Kehl et al., 2009).

Reality of death was identified for skilled nursing and inpatient hospice. Families had a hard time accepting the reality of dying and still experienced shock when the realization hit them. Feelings of frustration were evident if final communication between patient and family was prohibited. Placement-related regrets were reported for both inpatient hospice and skilled nursing facilities. Other themes that emerged were uncertainty, fulfilling family obligations surrounding death, caregiving tasks, and responsibilities. Of utmost concern was the absence of trust in care providers for those in skilled nursing facilities. If family could not be present, it produced a strain due to the absence of trust. Along those same lines was the theme of personal belongings, in which families described their sense of violation when belongings were stolen or destroyed. Lastly, insufficiency in communication with staff was identified, especially for those in skilled nursing facilities (Kehl, et al., 2009).

One seminal study surrounding understanding the needs of dying patients and their families was the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (Connors et al., 1995). This study highlighted the difficulties encountered in hospital settings. A follow-up study reported family member suggestions for improvement, which included facilitating improved interaction between the dying patient and family, improving interactions between caregivers and patients/families, and creating a setting that is more conducive to these interactions (Pierce, 1999). Families included in Pierce's study described the intense need to be physically close to their dying loved one and to be given instructions and opportunities to touch them and to receive more information about the process. Lastly, they wanted their loved one's personhood acknowledged and respected.

That study was consistent with Teno et al. (2001), a patient-centered family-focused focus group study on the quality of dying from the family perspective. According to that study, many people dying in institutions have unmet needs and concerns with quality of the care at the EOL, especially for those dying in hospitals or nursing homes (Teno et al., 2001). The perceptions of the families of quality of care differed by the last place of care, although ALFs were not included in that study (Teno et al., 2004).

Transitions from home or from ALFs to other health care settings at the EOL may have a profound impact on these families and on the quality of dying for older adults (Mezey et al., 2002). No studies yet have evaluated family perceptions of care during these transitions at the end of life that included ALFs. However, transferring to another setting of care has been shown to have burdensome consequences of stress, depression, financial burden, loss of personal possessions, and loss of personhood (Mitty & Flores, 2008; Mollica & Jenkens, 2001). Unfortunately, transitions in the last months of life are common, but they vary by state and are correlated with poor quality in EOL care (Gozalo et al., 2011).

Quality is defined by the IOM as "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge" (IOM, 1990, p. 376). Death as an outcome is difficult to measure from the patient who is dying; more relevant is the patient and family perceptions and satisfaction with the processes of care (Donaldson & Field, 1998). Quality at the EOL includes two separate constructs: "quality of care" reflects elements of a particular setting where the dying takes place, and "quality of dying"

includes the symptom burden that may be influenced by the care. The patient and family provide important elements and voices for defining the quality of care and quality of dying (Fowler, Coppola, & Teno, 1999).

The studies on dying persons and their families focused on finding a way to measure quality of care that was both patient-focused and family-centered (Teno et al., 2001). That research identified the key elements that constitute this type of care, which are (1) physical and emotional comfort, (2) shared decision-making, (3) focus on the individual, and (4) attending to the carers. Two key care processes run through those four elements: (a) informing and educating the family and (b) the coordination and continuity of care. The coordination of care among the last places of care is considered a key component of quality of care. No specific studies evaluated the effect of various settings and their impact on families (Teno et al., 2001).

A further study by Teno and colleagues (2004) examined family perspectives of EOL care at the last place of care. This study revealed that institutionalized residents had many unmet needs for pain and symptom management, emotional support, physician communication, and being treated with respect. Family members were more likely to report a favorable dying experience when a person died at home with hospice services (Teno et al., 2004).

Patient- and family-centered outcomes of care are central to developing quality care models. Families and other informal caregivers are crucial to the care and coordination of health providers, as well as the emotional support of these older adults in ALFs.

Family Caregiving

Family caregiving for frail older adults has increased dramatically over the past decade due to increased longevity and chronic illnesses in the frail elderly. The 2002 Health and Retirement Study (HRS), which provided data on older adults and their caregivers, included a sample that consisted of 16,997 adults age 55 and older (as cited in, Johnson & Weiner, 2006). Frailty was defined as having at least one personal care need required for independent living (Johnson & Weiner 2006). In the United States, there are 44 million informal family caregivers providing assistance with activities of daily living (ADL) (Administration on Aging, 2008; Levine, Halper, Peist & Gould, 2010) and 61.3 % of frail older adults receive assistance from only one unpaid caregiver, generally a spouse or a daughter. Women are the primary caregivers for most frail parents.   In 2002, two-fifths of adult child caregivers were between 30 and 49, which creates the dilemmas of work and children of their own. Of concern is that one-fifth of informal adult child caregivers are 60 or older and with many of their own health concerns. Stone and Clements (2009) examined caregiver burden, which has been shown to cause physical illnesses and psychological stress in caregivers that consequently lead to illness and even a greater risk of mortality (Blum & Sherman, 2010). These data provide a profile of family caregiving and the concerns; however, of interest to this study is family caregiving at the end of life.

The predominant focus of literature regarding family caregiving at the end of life surrounds care provided in the home along with transitions to end-stage caregiving roles in the home environment (Andreshed, 2006; Funk et al., 2010; Kellett, 1999; Penrod et al., 2012; Waldrop et al., 2005). There was also a primary focus on cancer patients in this literature. Funk et al. (2010) conducted a comprehensive review of qualitative research

of home-based family caregiving at the end of life from 1998-2008 that included 105 qualitative studies (18 of which were mixed methods) with a focus on family caregiving and palliative care, The majority of studies (35%) originated in the UK with 22% from the U.S.   The lack of diversity of patient conditions were of note, especially considering the primary focused heavily on cancer patients and also identified research gaps such as contextual influences on family caregiving at the end of life that create challenges and identified a need to examine the processes for families.

A review of published quantitative literature (1998-2008) of home-based family caregiving at the end of life identified 123 articles (17 mixed methods) (Stadjduhar et al., 2010). Compared to the quantitative literature reported in the last paragraph, the largest number of studies (45%) took place in the US. Similar to the qualitative findings, these authors identified the need for family caregiving research for nonmalignant terminal conditions. These authors suggest that little is known about how providing care at the end of lives affects bereavement outcomes. Findings regarding gender indicated that women providing care to family members have higher psychological distress and lower life satisfaction (Dunmont, Turgeon, Allard et al., 2006; Haley, LaMonde, Han, Burton & Schonwetter, 2003).

A model of caregiving through the end of life established a theory of "seeking normal" in the midst of the turmoil leading to the end of life (Penrod et al., 2012). However, despite this model's compelling evidence regarding the trauma experienced by familial caregivers, the process of relocation at end of life was not included, and thus it is yet to be determined whether "seeking normal" is applicable in the care transfer process.

Researchers examined daughters caring for dying parents and developed a theory of Relinquishing which illuminated the process of turmoil in experiencing loss and adjusting to a new reality (Read & Wuest, 2007). Findings from this study included the daughter's beliefs about filial responsibility and a sense of obligation to the dying parent. Read and Wuest (2007) emphasized that unsupported family care must not be taken for granted at the cost of depleting daughters who are caring for dying elderly.

One study explored factors that precipitated untenable caregiving crises resolved by relocation (care transfer) using Crisis theory, a conceptual framework that delineates the experiences a person undergoes when confronted with a dilemma that is seemingly unable to be resolved (Waldrop & Meeker, 2011). In Crisis theory, a resolution to the "unsolvable" problem – in this case a transition to a higher standard of caregiving – may yield both adaptive and maladaptive responses. The residents in that study were relocated to a hospice house, thus providing them with a knowledgeable, professional staff and compassionate end-of-life care, assets that were central to the residents (as well as their relatives) who achieved adaptive or "settled" responses. Maladaptive responses were a result of unrealized expectations due to fears of overmedication for hospice pain and symptom management, as well as excess unhappiness from the newly transitioned resident (Waldrop & Meeker, 2011).

Transitions to Nursing Homes or Hospitals

The literature pertaining to nursing home admission and placement has seen resurgence in publications in the recent past albeit still relatively sparse. The majority of the publications that were cited for these recent studies took place in the 1980s-1990s. The 19 studies reviewed ranged in years from 1991-2012. Three of these articles were

literature reviews with the most current review in 2008 (Kao, Travis & Acton, 2004; Ryan, 2002; Wilkes, Jackson, & Vallido, 2008). This literature also included eight studies outside the U.S. (three UK, one Ireland, one Korea, one Netherlands, and two Australia). Although there are different payment structures in these countries, the themes were similar to all other studies in that the conclusions focused on the importance of family carer support during transitions (Abarshi et al., 2010; Cheek & Ballantyne, 2001; Davis, 2005; Hanratty et al., 2012; Kellet, 2001; Kwon & Tae, 2012; Nolan & Dellasega, 2000).

The majority of the research articles surrounding nursing home placement were qualitative approaches with sample sizes ranging from 14-37, which is useful for uncovering the salient issues in these transitions. Three of the studies used a quantitative approach with large sample and two of those studies focused only on the dementia population evaluating the indicators and predictors of transitions for the last place of care for this population. Across all 19 of these studies, it was reported the high degree of psychological and physical distress of the relocation or transition for both the patient and the family members and many clearly documented the need for nursing supportive strategies. Two of the identified qualitative studies used a grounded theory approach. Davies (2004) examined an emergent fit of Meleis theory of nursing transitions with relative's experiences of nursing home entry and concluded Meleis' theory did not adequately represent the relationship between the staff and the families. This evidence was consistent with Ryan's (2002) literature review concluding the need for greater collaboration between families and staff.

Two studies used grounded theory methods and examined the processes in the decision-making of admitting an older relative to a nursing home. These researchers identified phase-specific strategies to address the feelings of isolation and distress and the inevitableness of the decision (Penrod & Dellasega 2011; Kwon & Toe 2012).

Researchers undertook a review and analysis of literature to identify research needs surrounding the quality of life and of dying for vulnerable older adults in different settings who are experiencing transitions. Those authors revealed that the science is weak surrounding this topic and identified that qualitative studies are needed that include the patient and their families and also identified setting specific research needs (Mezey et al. 2002).

Four studies evaluated transitions for hospice patients to inpatient facilities and one of these had a major limitation (Eagle & de Vries, 2005; Evans, Cutson, Steinhauser, Tulsky, 2006; Hurley, Strumpf, Barg, & Erserk, 2014; Waldrop & Meeker, 2011). Evans et al. (2005) used a grounded theory "approach" to interview caregivers of deceased hospice patients who transferred from home hospice to a hospital, a freestanding inpatient hospice facility, or a nursing home. A major limitation in that study was that only 1 family member agreed to be interviewed in which a relative was transferred to a nursing home, which gave a limited understanding of this phenomenon. The remaining three studies all focused on the transition to inpatient hospice settings. Hurley et al. (2014) explicated a process to develop a seamless transfer; however, results indicate the hospice setting is far more palatable to families than indicated in the nursing home literature, yet these preferences have not been fully explored, identifying a gap in understanding of the specific needs of these families.

Three studies used conceptual frameworks that included: 1) Meleis nursing transitions, 2) the process of transition based on the Theory of Personal Constructs and 3) Crisis theory. The theories that related to implications for family carers were Meleis middle-range theory and Crisis theory. Crisis theory is a process whose antecedent may be situational or developmental. Developmental antecedents are generally related to completion of life tasks; however, situational antecedents are unexpected such as in accidents or sudden illness, or unwanted moves to institutional care (Liken, 2001). Factors that mediate a life crisis include intrapersonal, interpersonal, or extrapersonal and will influence the response to the crisis. An individual's perceptions including their emotional and physical health are factors involved in intrapersonal mediators, while interpersonal factors include social support. Extrapersonal factors include resources, timing, and duration (Liken, 2001). In addition to those mediating factors is the success or failure of problem-solving methods that will either resolve or precipitate the continuation of the crisis and thereby influence a positive outcome or a negative outcome. Liken (2001) examined moving a relative to an Assisted Living Facility for older adults with Alzheimer's disease (AD) using Crisis theory as a guiding framework for analysis. AD behaviors and functional decline were the antecedents to the crisis and perceived lack of support in addition to physical exhaustion of the caregiver were mediators. The caregivers used problem-solving skills to make attempts to keep their relative at home and when these attempts failed, the resolution to the crisis was a move to an ALF. The majority of participants in that study had a positive outcome; however, the negative outcomes were unresolved guilt and distress (Liken, 2001). This research was limited to

AD, along with a move to a more home-like environment such as an ALF. The end-of-life context was not included in this study.

Although Meleis' theory is a useful tool in understanding the range of contexts and situations for nursing practice, as of yet, it has not included end of life as a context. Also, according to Davis (2005) who tested the theory in relative's experiences of nursing home entry, it fails to incorporate relatives' contribution to positive outcomes. Testing this theory with nursing support strategies with hospice care may yield valuable information about the bereavement outcomes for families. Crisis theory was used as a basis for the conceptual model of crisis resolution in end-of-life care developed by Waldrop and Meeker (2011). This model highlights the reciprocal nature of the suffering for both the patient and the family, which demonstrates the need for assessment and, similar to Meleis' theory, explicates a resolution as settled or unsettled; however, the mediator of the adaptive or maladaptive resolution is not identified and could be further tested. Developing a further understanding of the process families undergo during transitions at the end of life may add to these theories or generate new ideas and/or interventions.

A health care transition at the EOL to a hospital or nursing home is fraught with problems of continuity of care, medical errors, and the trauma of the physical transfer (Boockvar et al., 2004; Coleman et al., 2004; Gozalo et al., 2011). The unfamiliar settings and providers cause increased confusion for patients and their families, which results in miscommunication of goals of care. When the patient is a hospice patient, the goals of care are purely comfort; however, there are inconsistencies with these goals during transitions (Mitchell et al., 2009). These burdens are often highlighted in health

care transitions for those with advanced dementia. According to Gozalo and colleagues (2011), while these transitions vary by state, they are common and are markers of poor quality in EOL care. Gozalo et al., (2011) only examined nursing home residents with advanced cognitive impairment who were residents 120 days prior to death; death occurred in the last 3 days of life or if there were multiple hospitalizations in the last 90 days. Also examined was the lack of continuity in nursing homes after hospitalization.

Most studies on care transitions looked at transitions from home care to hospital or nursing home. The studies are limited on transitions from assisted living, especially at the EOL, for patients receiving hospice care. One intervention study focused on preparing patients and caregivers to take a more active role in their care and assert preferences. The researchers found that supporting patients and caregivers may impact rates of subsequent hospitalizations (Coleman et al., 2004). Patients and their caregivers are often the only common factor moving across sites of care. That study was designed to improve the quality of care transitions and was closely associated with efforts to support patient-centered care, shared decision-making, care coordination, patient safety, and cost control that are developing nationally (Coleman et al., 2004).

Conceptual Theories on Transitions

Transitions in care from one health care setting to another are a matter of vital concern to both health care providers and policy makers due to the lack of continuity in care leading to medication errors and hospital readmissions. The financial burden to Medicare was estimated at $17.4 billion in 2004 (Geary & Schumacher, 2012). One transition issue that may occur at the EOL for residents living in ALFs who are enrolled in hospice is an unnecessary transition to the hospital. This may occur due to the lack of

medical staff at ALF and the inability of the medical assistants to assess an individual, which leads to a 911 call. Increasing financial burdens to the residents due to increasing care needs may influence the transition to another facility, and a nursing home may be the only choice. In order to receive the Medicare benefit of nursing home care, the patient must be transferred from the acute care setting, thereby incurring two moves in order to avoid the financial burden.

Nurses play a considerable role with patients and their families who are undergoing care transitions because maintaining therapeutic care during the transition is a central concept in nursing. There are many times when patients and families are undergoing transitions, and it is important not only to focus on a specific type of transition, but also to recognize patterns of transitions: single or multiple, sequential or simultaneous, and the relationships between events. Meleis et al. (2000) argued that the issue at hand was the vulnerability of the families and patients related to these transition experiences. The vulnerability may be related to environmental conditions that expose individuals and families to potential problems with recovery or in the case of caring for a dying loved one, delayed or unhealthy coping (Meleis et al., 2000).

Transitions of many types are under the purview of the nursing domain because the person in the environment is essential to understanding the actual or potential effects on health (Chick & Meleis, 1986). Transitions are both a process and an outcome that can be translated to assessment for nursing practice and create an understanding of how a person manages an outcome and which processes led to that outcome (Chick & Meleis, 1986). In the context of this research, the dying patient and their relative are the unit of care. The outcome for the elderly person is death, which is hard to measure; however,

the impact of the quality of that death may be measured in the bereavement and health outcomes for the family caregiver. End-of-life care has not been examined as a context in transitions to other health care environments at the end of life in order to measure the outcome of quality of death and its' positive or negative consequences for family members.

The middle-range theory of transition in nursing was developed that provided a broad framework for viewing transitions. The three main components of the theory are: (1) the nature of the transitions, (2) conditions for transitions, and (3) patterns of response. All of these components are affected by nursing therapeutics. Nursing therapeutics is provided by the nurse's actions of promoting comfort and showing empathy and respect (Meleis et al., 2000).

Researchers extended and refined the original transitions theory by examining the results of five different research studies examining transitions. Those researchers examined the original middle-range transition theory framework. They further developed the properties of the main components of the theory from these various studies. Each study expanded on the concepts under each component. The nature of the transitions includes concepts such as awareness, engagement, change and difference, time span, and critical points and events. The conditions of the transition include facilitators and inhibitors of personal conditions, including meanings, cultural beliefs and attitudes, socioeconomic status, and preparation and knowledge. Other facilitators or inhibitors are feeling connected, interacting, location and being situated, developing confidence, and coping. The third component contains the patterns of response, which include both process and outcome indicators. This theory is important because the researchers noted

that the diversity, complexity, and multiple dimensionalities of transitions experiences need further exploration (Meleis et al., 2000). Transitions at the EOL from ALFs to nursing homes, hospitals, or other care facilities could be an area to study in relation to this theory. As noted, there are other ways of studying care transitions and improving transition outcomes. Researchers proposed to integrate the theoretical components of both the classic theory on transitions in nursing along with concepts of complex adaptive systems from complexity science (Geary & Schumacher, 2012)

The research involving care transitions largely surrounds hospital readmission. One intervention study involving older patients and their caregivers tested an intervention to encourage the caregivers to take a more active role in older adults' care (Graham, Ivey, & Nenuaser, 2009). This intervention also included a transition coach. Two qualitative studies examined care providers' decision-making to identify patient needs during transitions (Graham et al, 2009; Naylor, Stephens, Bowles, & Bixby, 2005). Davies (2005) explored relatives' experiences of the move to a nursing home to examine the extent to which the data fit Meleis's middle-range theory of nursing transition. Other literature on transitions includes the process of how caregivers make the transition to end-stage caregiving using a stress process model.

Does a transition in the last month of life affect the quality of care and the quality of dying? The fact that people are living longer has led to an increase in the incidence of Alzheimer disease and other dementias, which are a significant cause of institutionalization, disability, and mortality (Aaltonen, Rissanen, Forma, Raitanen, & Jylha, 2012). Some ALFs have memory care units and can care for people with cognitive impairment up to a certain point. A recent study compared the number and timing of

transitions between care settings among older people with and without dementia in the last 2 years of life and found the most vulnerable times for transitions were in the last 3 months of life, when death became closer (Aaltonen et al., 2012). The rates were higher for those not living in residential facilities overall; however, toward the EOL the rates were the same for both community-dwelling and residential care facility people with dementia when adjusting for age and gender.

<div align="center">Summary</div>

Aging older adults are vulnerable as they progress towards the end of life. Although families reported that dying at home with hospice services is the most favorable condition, many will die in residential facilities [assisted living (ALFS) and skilled nursing homes/nursing homes (SNF/NH]. Research concerning the impact of settings and transitions on the quality of life and the quality of dying for older adults is weak especially from the patient and family-focused perspectives. Since ALFs have only been in existence for the past 30 years, research concerning outcomes of EOL care is limited. Of interest to this study are constructs surrounding aging in place; however, extending this philosophy to dying in place is relatively unexplored. There are only a dozen studies that evaluate resident transitions from ALF; however, they involve descriptive statistical data and no information of the impact on residents and families. There are numerous studies involving family perceptions of EOL care in nursing homes; however, gaps in the literature exist on EOL care, including hospice in ALF and the family caregiver's experiences through care transitions.

Thus, this study was a necessary step in illuminating the processes, stages, and phases of transitions that occur at the EOL, as well as highlighting the consequences of

these actions from the bereaved family members' perspectives, as well as hospice nurses' perspectives. A better understanding of family's needs is essential to informing practice, policy, and research. The following chapter explains the Glaserian grounded theory research methodology used in this study.

CHAPTER 3

METHODS

Grounded theory is essential to the discipline of nursing because it enables the understanding and conceptualization of the patient's responses and experiences of events (Morse, 2001), and directs the examination of processes, stages, and phases as well as the consequences of the actions and behaviors (Stern & Porr, 2011). Since its inception in 1967 by Glaser and Strauss, this qualitative, inductive approach to research has been modified and adapted as part of the evolution in philosophical trends in the scientific community. For this study, I utilized classic Glaserian grounded theory (Chenitz, & Swanson, 1986; Glaser & Strauss, 1978; Martin & Gynnild, 2011; Schreiber & Stern, 2001; Stern, cited in Morse et al., 2009) that provided a way to systematically generate theory from data.

Glaserian Grounded Theory

Glaserian grounded theory is known as classic or traditional grounded theory and has a particular philosophical lens compared to Straussian (Strauss & Corbin, 1998) and constructivist grounded theory (Charmaz, 2000). Glaserian grounded theory's philosophical lens is characterized as "critical realism" and "modified objectivist," wherein the social world can be known in an objective reality, while the researcher remains the neutral observer who discovers data and hence develops theory (Ghezeljeh &

Emami, 2009). Strauss and Corbin (1998) assumed a relativist or subjectivist position, while Charmaz's (2000) constructivist viewpoint makes the assumption that truth is co-created through the interactive process of researcher and participant constructing a shared reality (Breckenridge, 2012). Glaser and Strauss (1967) originally suggested that the researcher, as an instrument, must remain objective; in comparison, constructivist grounded theory interprets the shared meanings of the participants, researcher, and the observations.

From the epistemological stance of symbolic interactionism and pragmatism, inquiry into the reality, perceptions, and beliefs of daily living may be interpreted and provide explanation of the experiences, what people find important or problematic, and what the processes are for finding solutions to these issues (Stern & Porr, 2011). Thereby, the goal of this Glaserian grounded theory is to conceptualize the latent pattern of behavior that emerges from the data, and to abstract from that, rather than develop an interpretive understanding of participants' meanings (Breckenridge, 2012).

For the purposes of my research study, Glaserian grounded theory was the optimal method for understanding transitions in social processes. This method is very useful for understanding what is going on in a substantive area in order to explain and interpret (Glaser, 1978). Inherent in this method is the ability to develop the basic social processes from data and to identify and describe the phenomena, as well as the trajectory of change (Morse et al., 2009).

A grounded theory consists of the following components: (1) phases and stages; (2) the basic social process, which is the theme that runs through the entire process and holds it altogether; and (3) the theory that is generated from the data (Glaser & Strauss,

1967). This basic social process or core category explains a significant portion of the variance and will provide an understanding of the circumstances and stages of the trajectory that families endure during times of transitions for their family member.

Morse et al. (2009) described grounded theory as a powerful tool enabling the synthesis of data and the development of concepts and middle-range theories that will be generalizable to future instances. In this present study, the perspectives of two groups was developed: (1) the family, speaking as proxy for the patient, as well as providing the perspective of significant others; and (2) hospice nurses, who provided the perspective and experiences of professional carers. These perspectives were examined and interpreted to develop a situation-specific theory of receiving hospice care in this difficult transitional environment, as well as illustrate the role and action of hospice nurses in this process.

The Development of Grounded Theory

Grounded theory was developed by Glaser and Strauss (1967). Glaserian grounded theory, as an exploratory method, is not descriptive; rather, it is the study of a concept with the purpose of developing a middle-range theory (Glaser, 2001, 1978). This concept is derived from the name of a pattern, and that pattern has explanatory power to describe the actions and consequences of behavior. It is therefore more abstract and at a higher level than description. Glaserian grounded theory does not traditionally begin from predefined concepts; however, it may add to existing concepts and theory. In Glaser's classic book *Theoretical Sensitivity* (1978), the advice given is to forgo the literature review in order to formulate original interpretations and to control for bias. However, it might be neglectful to forgo relevant literature about the topic, which may

facilitate the conceptual development of the project. For instance, in this study,

understanding the "state of the science" regarding families experiences with hospice and

transitions was a necessary step in the methodology. From this understanding of the

literature, a sensitizing concept may be identified, which is an idea or understanding the

researcher has developed about the phenomenon and seems salient (Schreiber & Stern,

2001). It is necessary to be cautious to bring these concepts in only if support for those

concepts is found in the data. The researcher must carefully scrutinize against favoritism

towards certain theories and to recognize assumptions and beliefs and to bring these out

in the writing of the analysis.

Theoretical Sensitivity

    As previously discussed, it is necessary to use *a priori* knowledge to understand

the substantive area of study. Also, it is necessary to guard against any potential threats

to the validity of the study. Theoretical sensitivity is another way of controlling for bias;

it is the ability to move inductively from the specific to the abstract and build the theory

from the data. One way to incorporate theoretical sensitivity is to use memos about *a*

priori theories and to compare them against data that have been gathered. This method

allows for all possible explanations for what is emerging from the data, but particularly in

light of negative cases (Schreiber & Stern, 2001). In this way, grounded theory is not

only a method but a way of thinking about the data in an abstract way (Morse, personal

communication, Morse, 2001). Thus, GT is experiential and a researcher must have the

ability to develop theoretical insight, conceptualize, and organize as well as visualize and

think multivarietely (Glaser, 2004)

The first step in this study was to identify a problem. The problem was introduced in Chapter 1 and further examined in the Chapter 2. This research was conducted to understand the process of transitioning to residential and institutional care facilities at the EOL from the perspectives of the family members and the hospice nurses.

Participants and Definitions

Family. For the purposes of this study, bereaved family members who were included in this study may have included non-blood relatives or proxies; however, all were blood relatives to the best of my knowledge.

Hospice nurses. A nurse who currently works, or has previously worked, for a hospice agency were included. These nurses were not matched to the family member as the health professional involved in their care.

Care transitions. Care transitions will be defined as movement from one "residential" setting to another.

Residential care facilities. These were primarily ALF and indicated assistance with activities of daily living. Nursing homes can be included in this category; however, the major difference is in nursing care and the payer sources.

Institutional care. For this study, this term includes Skilled Nursing and Nursing Home care. Nursing care provided and paid mainly through Medicare/Medicaid.

Nursing homes/Skilled nursing facilities. These terms are included in the above definition of institutional care and may be included in residential care due to the umbrella term of long-term care.

Theoretical Sampling

Grounded theorists typically call for the use of theoretical sampling, which is the process of simultaneously collecting and analyzing data and sampling criteria, and may shift sampling due to the emerging theory. As the theory was emerging, it became evident that all transitions to residential care facilities were distressing and not limited to just ALF.   In this way, it allows for seeking more than one source of data to better interpret the variation in the data. As I will continually ask "What is going on here?" I wanted to explore differing circumstances, and sought out specific informants, such as a hospice administrator, hospice social worker, and Skilled Nursing Facility social worker as well as Assisted Living Facility nurse. Initially, the sample was purposively selected and then I used theoretical sampling as I simultaneously collected and analyzed my data.

Sample and Setting

The sample from this study was recruited from Idaho agencies and facilities in order to capture data specific to Idaho. Initial sampling was purposive. Purposive sampling was used with participants who can yield the most information about the identified process in order to confirm the trajectory through rich description of the stages as they are experienced (Morse, 2007). The purposive sample of bereaved family members (n=14) were recruited from local churches and the College of Health Science at Boise State University. Permission was obtained to send an e-mail to all College of Health Science faculty and staff with an explanation of the study, and interested persons responded to the e-mail if they wanted to participate in the study. Two participants were recruited from this area. For the church communities, a letter was sent to faith community nurses, along with advertisement in the church bulletin (Appendix B). Faith

community contacted families and explained the study and inquired if they were willing to participate in the study. Two participants were recruited from this area. Heart 'n Home Hospice & Palliative Care contacted families that met the inclusion criteria to invite them to participate in the study and 3 participants were recruited. Also, Horizon Home Health and Hospice was added as a study site in increase participation, yielding an additional 7 participants. Both groups forwarded the names and phone numbers of interested volunteers to me so that interviews could be scheduled. (Appendix C)

The hospice nurses (n=13) were recruited from two local hospice agencies in Ada County, Idaho. The Hospice and Palliative Nurses Association (HPNA) Idaho Chapter also supported recruitment of hospice nurses. The hospice agency as well as the HPNA Idaho Chapter provided contact information for their nurses, and an e-mail was sent with a description of the study and an invitation to participate. An e-mail reply indicated their willingness to participate, and an interview time was scheduled at that time. Data from the two samples were kept separate and analyzed separately to avoid contamination and to enable comparisons.

As mentioned, initial sampling of both hospice and family members was purposive; however, as the emergent theory became evident, theoretical sampling techniques were used to direct the sample to better understand the variation. A hospice social worker (n=1) was recruited by word of mouth as well as a Skilled Nursing facility social worker (n=1) and an Assisted Living facility nurse (n=1).

Inclusion criteria for family members. The relatives' death must have occurred from approximately 6 months to 1 year prior to this study, but exceptions were made to this time constraint if the person was willing to be interviewed. Initially, their relative

must have been transferred from an ALF to another health care setting during the last months of life and enrolled in hospice care, but the analysis and theoretical sampling led to inclusion of other care transitions such as from home to either an ALF or a SNF/NH. The study was also updated to include bereaved family members whose relative was not enrolled in hospice. The family member or significant other were 21 years or older and English-speaking, and had knowledge of and observed the care received during the last year of life at these facilities; however, she or he did not need to be the primary caregiver.

Inclusion criteria for hospice nurses. The hospice nurse must have been caring for an ALF resident who was in hospice and transferred from the facility in the last months of life, or cared for in the home and transferred to an ALF or SNF/NH. The nurses need not have cared for the participant family members loved one, but must be able to discuss the care of a resident(s) who had been transferred at end of life.

The face-to-face interviews took place at the most convenient location for the family and the hospices nurses, but if the person was not able to meet (for instance, lived some distance away), arrangements for other mechanisms, such as telephone or Skype, for the interviews were made.

Those families who indicated a willingness to participate in the interviews were contacted by telephone for an appointment to conduct the interview, and the hospice nurses were contacted by e-mail or by phone. I explained the goals of the research, and their willingness to participate was determined at that time. If the participant agreed to an interview, they were asked to identify the most convenient place for the interview. A letter describing the study and confirming the time and place of the interview was sent to each potential participant. A signature was obtained on the informed consent document,

but not long into the study, it was discovered cover letter consent could eliminate the need for a signature and that document was developed (see Appendix E) and a copy was provided to the participant. If the interviews were conducted by phone, the cover letter consent form was either mailed or emailed to the participant.

At the time of the interview, a verbal explanation of the study was provided along with time to answer any questions. Unstructured interviews with a bereaved family member could be conducted in the researchers office at Boise State University, or, if the participants preferred, at a place convenient and private. All interviews were digitally recorded.

Data Collection

Interviews commenced with baseline demographic questions, including age, relationship to the deceased, and place of death of the deceased, time since death of loved one, and advanced directives. The unstructured interviews followed with a broad question "tell me about your [decedent]'s last month of life" asked as gently as possible. The interviewer assumed a listening stance, asking minimal questions without "leading" the participant in order to obtain the participant's perspective. This approach increases the validity of the data (Corbin & Morse, 2003; Morse, 2012).

After the initial interview, data were analyzed. As I attained understanding of the phenomenon, guided questions emerged, and were validated with other participants. ("Some people tell me…. Is this what it was like for you?") The interview for the family members also included a number of guided questions that were helpful for eliciting information when the participant needed to be cautiously redirected back to the research topic.

Such guided questions included information obtained from the literature:

1. Tell me about how the transition affected you and your family member.

2. Tell me what is was like for your relative to have to leave their home or ALF "home."

3. Tell me about the experiences in the new healthcare facility.

4. Did your family feel they had the necessary support from the hospice nurses?

5. If they did not have hospice care, what kind of support did they receive?

6. Tell me anything that made this time more comfortable for your family member. Or more difficult?

It was anticipated that open-ended unstructured interviews could last more than 2 hours; however, interviews averaged between 45 and 90 minutes.

Data Analysis

Demographics

The sample that was interviewed consisted of 30 participants (14 bereaved family, 13 hospice nurses, a hospice social worker, a SNF/NH social worker, and an ALF nurse). Two hospice nurses and 3 families members received a second interview as well as theoretical group interviews of 2 hospice nurses and 2 family members, with a total of 36 interviews (n=39). One family interview included a husband and wife who experienced caring for three members of their family who were transitioned and 1 family member transitioned both of her parents at the end of life. And at the end of the data collection period, when the model was developed, it was shared and discussed with 2 family members and 2 hospice nurse to obtain any additional data and to further define the theory.

The majority of the participants were female and adult daughters. The average age of the participants was 61.7 years. The time since the relative's death ranged from 6 months to 8 years with an average of 30 months. Six participants transitioned their family member from an ALF to a SNF/NH, 1 from home to ALF to SNF/NH, 1 from ALF to SNF/NH and another SNF/NH, 1 from home to ALF, and 7 from home to SNF/NH. The following table represents the bereaved family member demographics (see Table 1).

There was only 1 male hospice nurse and the rest were female, including the SWs and ALF nurse. The average age was 47 years old and experience ranged from 1 year to 35 years. The education ranged included 4 Associated Degree RN, 5 Bachelor Prepared RNs, and 2 Nurse Practitioners, 1 with a Master's Degree in Nursing and 1 in a Master's program. Nurses reported average time patients spent in the new location from the transition and not related to one specific patient. Time in the new location ranged from 2 weeks to 9 months. Table 2 represents the hospice nurse demographics.

<u>Transcription and Data Preparation</u>

Analysis of data in grounded theory requires the researcher to have as few predetermined ideas as possible, allowing the researcher sensitivity to the data and remaining open to what is emerging. The analysis systematically generates theory from the data. First, all interviews were transcribed by a research assistant verbatim, de-identified, and initially it was identified that data would be entered into NVivo 9.0 qualitative data management software by the interviewer, however, as directed by my chairperson and with consideration of my novice abilities, it was recommend to analyze the data without the software. Each transcribed interview was reviewed by a research

assistant for accuracy and edited as needed. According to the principles of grounded

theory, analysis began as soon as the first interview was completed and continued

concurrently as the interviews proceeded. Glaser and Strauss (1998) suggested

comparing the first two interviews for similarities and differences.

The goal of grounded theory was to generate theory that explained the pattern of

behavior that is problematic for those involved, such as the bereaved family members

(Glaser, 1978). Data were analyzed inductively line-by-line using open coding, which

allowed for theoretical sensitivity to identify important concepts. Each data set was

analyzed independently and kept separate for the bereaved family members (Aim 1) and

the hospice nurses (Aim 2). They were linked analytically to produce the situation-

specific theory (Figure 1).

Open coding generates codes line-by-line; as themes emerged and become

saturated, it generated the categories that help to explain the basic social processes of the

problem. The coding led to the development of the core category as it becomes evident.

Most other categories were related to it in some way. These core categories identified the

stages and sequencing of the events and allowed one to follow the changes over time

inherent in the basic social process and the development of the theory. A basic social

process (BSP) is one type of core category that accounts for the change that occurs over

time (Chenitz & Swanson, 1986).

The second phase of coding involves axial coding, which identified the specific

properties of the core category and theorizes the relationships to other core categories

(Lewis-Beck, Bryman, & Liao, 2004). The constant comparative method along with

memoing techniques were used for analysis to identify similarities and differences in each level of analysis.

The third type of coding in the analysis was selective coding, which further theoretically identified the relationships among categories. Initially, the substantive codes conceptualize the area of research whereas theoretical codes conceptualize how the substantive codes relate to each other as a hypothesis and integrated into a theory (Glaser, 2007). These theoretical codes give a broad picture and give the researcher a new perspective (Glaser, 20007). Memoing involved notes written by the researcher throughout the process of data collection concerning insights and also addressed any preconceived assumptions and bias. The codes and categories identified were compared to the existing literature for the emergent fit of the theory.

One aspect of the data that was considered in the analysis was the use of *shadowed data* (Morse, 2001). The shadowed data were evident when it was necessary to obtain data about the deceased loved one's experience. It was data reported by others about their relative's perspective and experiences and in the case of the hospice nurses, about the experiences of patients "in general" as well as particular instances, without identifiers. Morse (2001) advises when using grounded theory that this information may expedite the research and direct theoretical sampling. It also facilitates the organization of the sampling frame. These data were used as a form of concept analysis. Data were sorted into the nurses' perspective of the participant about the transition versus the views of their relative who has since passed away. This framework was used for other instances of analyzing similarities and differences and also assisted in theoretical sampling through constant comparative method.

As a means of validation of the emergent theory, at the end of the study, theoretical group interviews (focus groups) were performed with selected participants to refine the theory. The selected participants were invited to participate and the resultant theory presented. Participants were made aware through the consent process of the potential need for additional information, and (as in focus groups), that others will be there to discuss these data. They were provided the information in the consent and were able to decline to attend or refuse to discuss the data.

The analysis was conducted under the guidance of Dr. Janice Morse, Chairperson of this Dissertation Committee and an expert in grounded theory method. Dr. Morse reviewed the coding schema that was developed; however, because of the interpretative nature of this research, interrater reliability was not measured. An audit trail through the use of memoing and field notes was created. All data were recorded systematically and verified through multiple sources. The family member data set and the hospice nurses data set were analyzed, separated, and compared for similarities and differences with family data.

Open Coding and Interpretive Coding

The method of coding data incorporated processes of open and interpretative coding. To demonstrate this process, I will include a segment of data analyzed in Table 3. I used open coding to group these participants responses and the participants who reported them during the first round of opening coding. A major step in open coding is line-by-line; however, a substep is underlying key phrases and restating those phrases such that I could begin to understand what the elements of the transitions were for families.

Initially, I began to look at the contextual factors that were instigating the transitions and separated these out to another category pertaining only to issues in ALF that included regulations and staffing and financial resources; however, as I compared the two data sets, it became apparent that the same issues were occurring when families members were experiencing transitions from their original home that lead to *increasing care needs*. The antecedents were similar in that the needs of their family member were increasing as well as the breaking down of the caregiver's ability to provide the care and the financial burdens of hiring additional caregivers. Table 3 presents an abridged version of this analysis.

Next it was important to understand the concepts that were occurring that would further explain what the participants were saying. This is where theoretical sensitivity, along with an unbiased approach from the researcher, were important. Now I was ready to move to interpretative and axial coding and consistently asking myself, "What is going on here?

This is an iterative process and thereby the steps of developing codes concepts and categories are not sequential. Axial coding identified specific properties and led to collapsing initial codes into categories (codes that were clustered into concepts) and continued to theorize the relationships among categories, which aided in the development of the core category of guilt (see Table 4). The large categories initially developed for the family member data set included Elements of the Transition, Emotions of the Transitions, Decisions and Decision-making, Making Promises, Death Sentence, Caregiver Burden, Issues in the ALF, Feeling Guilty, and Hospice Care. The hospice nurses reported similar data and after coding, the large categories included Family Decision Making,

Truth in Marketing (ALF), Hospice Nurse's Role, Family Dynamics, Issues in the Environment, Elements of the Transition, and Aging in Place. Memos were made throughout as well as the constant comparative method, comparing incidents to incidents, and categories to categories and identified similarities and differences in each level of analysis. This constant comparison of these incidents and with incidents not yet coded began to generate the theoretical properties of the category (Glaser, 1978). Once the concepts were identified into categories or classification of the concepts, generalizations were made about the categories and explicated in a storyline (Eaves, 2001). For instance, Emotions of the Transition was a large category and it was compared with the Feeling Guilty and Making Promises category while memos and theoretical codes began to abstract these into concepts asking analytic questions of the data: Is this powerlessness or helplessness? If there is anger, who is angry? What are the attributes of the guilt?

The third type of coding in the analysis was selective coding, which further theoretically identified the relationships among categories and further explicates the storyline by determining the properties and dimensions within the categories. Initially, the substantive codes conceptualized the area of research, whereas theoretical codes conceptualized how the substantive codes related to each other as hypothesis and integrated into the theory (Glaser, 1978). Once the categories were reduced to subcategories and the characteristics, properties and dimensions were delineated, and the core category was developed (see Table 5). For instance, Decision Making, Caregiver Burden, and Feeling Guilty were compared as the storyline was being explicated. Theoretical codes of guilt, regret, and duty or obligation were being examined, and the dimensions of guilt were delineated for the types of guilt and when this guilt was

prevalent and the theoretical codes assisted in explaining the types of guilt (spoken, unspoken, observed, and inflicted) that were prevalent. Table 6 represents these dimensions of guilt and the development is described in Chapter 4, *Living Through Transitions of the Dying Elderly: The Changing Nature of Guilt in Family Caregiving*.

These theoretical codes gave a broad picture and a new perspective (Glaser, 1978). Memoing involved notes written by the researcher throughout the process of data collection concerning insights and addressed any preconceived assumptions and bias. The codes and categories identified were compared to the existing literature for the emergent fit of the theory. As the stages in the storyline were developed, gerunds (Glaser, 1978, 1996) are applied indicating actions and change (Morse, 2001).

The hospice nurses interviews provided shadowed data for the family's experiences. Analyzing the hospice nurses data set also supported the theory and the data sets were compared side by side once the stages were identified. The role and actions of the hospice nurses were described in Chapter 5. Families identified that hospice care provided crucial support during these difficult transitions. The most substantial finding regarding hospice nurses actions and roles was during the dying process when nurses providing information and coaching to assure the family's witnessed a "good" death. This appeared to mitigate and resolve lingering guilt by justifying the transition and making meaning of the event. This area of the model needs further study to determine if witnessing a "good death" does in fact have an impact on the bereavement process and the resolution of guilt.

Diagraming and Writing

At the outset of the study, diagraming was a critical step in the design, as shown in Figure 1. An "armchair walkthrough" (Morse, 1999) of the study assisted in creating the design; however, it was also essential in explicating the storyline as well as developing the theory. Many iterations of the model were diagrammed to analyze and abstract the concepts and theory. In addition, writing about process also helped clarify meaning and interpretation of the theory.

Theoretical Saturation

As the sampling and analysis occurred concurrently, theoretical saturation was reached when no new data emerged and all concepts and properties of the theory were well developed. After verification of the relationships between concepts and the linkages between them was completed, then no additional data will be needed.

Once theoretical saturation was reached, differences in the trajectories were examined for negative cases. The results were integrated to develop a grounded theory of the basic social psychological processes occurring for patients receiving hospice care and their family members during EOL care transitions.

Rigor

Qualitative research has had to refine and define the criteria of evaluating and legitimizing qualitative research, and there are a multitude of ideas posited for criteria of good qualitative research (Cohen & Crabtree, 2008). Although the terms are different and varied, the significance is vital to the standards of rigor and validity (trustworthiness) of qualitative evidence. Guba and Lincoln (1989) first introduced this concept of "trustworthiness," which contained the four aspects of credibility, transferability,

dependability, and confirmability. These four aspects are becoming less used, as it becomes necessary to use the same terminology as for quantitative researchers; therefore, it is more appropriate to use the term "validity."

Verification and validation of the data begins with the research design and was iterative (as opposed to the linear sequencing of a quantitative study) and should be an "addition to existing knowledge through its contribution to theory, explanation of a phenomenon, or addition to methods used in qualitative inquiry" (Meadows & Morse, 2001, p. 187).

In grounded theory, this iterative process added to the verification of the data by the rigor involved in following this method of open coding, axial coding, constant comparison, and the development of categories and theory. The theory is supported by the literature to give validity to the accuracy of the findings by demonstrating the fit with existing literature or how and why they differ (Creswell, 2009). As previously mentioned, the theory was validated through the use of theoretical group interviews.

Human Subjects and Ethical Considerations

The study was reviewed and approved by the University of Utah Institutional Review Board (IRB). As Principal Investigator, I assumed the responsibility for adherence to regulations regarding the use of human subjects in research. I have been formally trained in the use of human subjects, IRB, and HIPAA certification programs.

The subjects for this study were bereaved family members of residents who were transferred from hospice care to and between home, ALF, and NH care facilities at EOL for Aim 1. Family members were recruited from two community settings. One setting was a church, and identified families were contacted through faith community nurses,

along with advertisement in the church bulletins. The other setting was from Boise State

University College of Health Sciences. After University approval, all faculty and staff in

the college were sent an email explaining the study and asking to reply if they were

interested in participating in the study. For Aim 2, hospice nurses were recruited from

local hospice agencies.

Risks to Participants

There was a risk of emotional upset, discomfort, or stress. The purpose of the

study was described to the subjects, and participants were provided the opportunity to

withdraw from the interview or study at any time. Every precaution to protect the

autonomy of individuals was taken and that consent was informed. At the first contact,

the purpose of the study was explained clearly, and the right to refuse or stop the

interview at any time was emphasized. The subjects were informed about the nature of

the study and the potential risk of emotional upset, discomfort, or stress. The participant

had the ability to stop the interview at any time during data collection. They were

provided numbers for grief counseling as needed. Also, they were provided time for

debriefing of the interview.

All names or other protected information were not used. All participants

received an interview code number. All identifying information was kept in a password-

protected computer, and all precautions to protect the privacy of the individual were

taken. Written notes and memos were kept in a locked file cabinet. Once the study is

finished, the identifying information will be destroyed.

The participants of this study were bereaved family members of residents who

were transferred from hospice care at home or at ALF at the EOL who were able to

consent to participation in this study. The sample of hospice nurses from the hospice agencies were contacted by e-mail and invited to participate in the study. At the time of the interview, the study was explained, and they received and signed a written consent explaining the risks and the benefits, the protection of anonymity, and their ability to stop the interview at any time and withdraw from the study. I updated the form to a cover letter consent that enabled the participants to verbally consent and then a copy was made available for the participants (Appendix E).

An amendment to IRB was made to increase recruitment by adding an incentive of a $25.00 gift card to bereaved family members for their participation in the study. Seven family members received gift cards.

Implications of the Study

The Agency for Healthcare Research and Quality (AHRQ) is particularly interested in the issues facing policymakers in redesigning care to focus on patient-centered and family-focused care (Kass-Bartelmes & Hughes, 2003). In the potential care redesign, the role of nursing in ALFs may be greater in the future. An understanding of the care needs of families and patients could influence models of nursing care for these facilities. The stages of these care transitions developed from this grounded theory provided a foundation for a situation-specific theory that may be replicated and evaluated for other participants in future studies.

The results of this dissertation consist of two articles for publication as agreed by the committee. One article presented the findings and grounded theory of the family members' perceptions of care of the health care transition at the EOL. The second article presented the finding of the hospice nurses' experiences of care surrounding health care

transitions at the EOL and the actions of these nurses in the process.   The final chapter of

the dissertation includes the summary of findings in the discussion, limitations,

recommendations for future research, and conclusions.

Table 1

Bereaved Family Members Demographics

Age groups	Relationships	Locations of Transfer	Time in Hospice
50-55 (4)*	Daughters (1) Son (1) Daughter-in-law (2)	Home to SNF (5)	Barely a day (1) No hospice (2) 2 months (2) 1 year (2)
56-69 (4)*	Daughters (4)	Home to ALF (2)	1 month (1)
	Daughter-in-law (1)	ALF to SNF (1)	6 months (1)
		ALF to Psychiatric Hospital-to different ALF (1)	No hospice (1)
		ALF-Hospital-SNF-ALF-SNF (1)	2-3 weeks (1)
		ALF-SNF-ALF-Daughter's home (1)	94 days (1)
		Daughter's home-ALF-SNF (1)	
60+ (5)	Daughters (4)	ALF to SNF (3)	2 months
	Daughter-in-law (1)	ALF to SNF to memory care (1)	3 months
		Home to ALF(1)	5 years
			6 months (2)

*The son transferred his father, sister, and brother and one daughter transferred her mother and father.

Table 2

Hospice Nurse Demographics

	Hospice	Social Worker and ALF Nurse
Age Range (in years)		
25-29	0	1
30-34	1	1
35-39	3	0
40-44	0	0
45-49	1	1
50-54	3	0
55-59	1	0
60+	2	0
Education Level		
Associate Degree RN	3	1
Baccalaureate RN	6	
Masters RN	1	
Master's Program	1	
Nurse Practitioner	3	
Licensed Social Worker		2
Years of Experience (in years)		
1-5	6	2
6-10	4	1
11-20	2	0
20-30	2	0
30+	1	0

Table 3

An Example of Initial Coding (Interpretive and Memoing)

PG 4: And they tested her for MRSA one day, and she tested positive. They called me at 9 o'clock at night. <u>I had to go and remove her from XX[ALF] and take her to (City) to the other facility. They wouldn't allow her to be there--they said it had be done within an hour</u>

My thinking is she had to have had it two to three days prior to. It doesn't just pop up in an hour

ELEMENTS OF THE TRANSITON

MEMO: REGULATIONS MAY BE UNBEKNOWNST TO FAMILIES AT THE OUTSET, CAUSING TRANSITIONS?

PG 4: <u>She was like the next week, maybe two weeks, that she was there they *flipped her out of that onto the floor.*</u> And she never really regained consciousness from that. Like <u>three days later she passed away</u>

ACCIDENT IN NEXT TRANSITION TO SNF

MEMO: FAMILY FEELS TRANSITION WAS UNCESSARY AND CAUSED AN UNTIMELY DEATH. EXPECTED DEATH VS UNEXPECTED DEATH?

Table 4

Elements of the Transitions
The following table lists the codes extracted and their classifications

---

Expense of the transition   Resources
Regulations due to MRSA   ALF regulations
Required more care -   **Increasing care needs**
Level of care not adequate for Parkinson resident   **Increasing care needs**
Good relationship with ALF staff   Liked where they were at
Losing more autonomy – declining   **increasing care needs**
Move her to memory care without memory issues   Family questioned decision
NOTE: This was an educated family
professed to be a dementia care center   **increasing care needs**
Inadequate care in ALF – cause of death   regulations affected death
ALF couldn't care for her anymore   **increasing needs**
AFTER TRANSITION
Transition caused decline   effect of the transition
Big change after transition   decline after transition
Keeping things familiar during transition   normalizing
Decline and plateaus for each transition   decline with transitions
Moving from room to room – attachment to her roommate – more transitions
Transitions may bring families together – wake-up call – they really are dying
family dynamics

Table 5

Developing Categories

Elements of the Transition	Description	Category/Stage
Expense of the transition	Resources	Financial breaking down
Regulations due to MRSA	ALF Regulations	Break down
Required more care	Increasing care needs	Breaking down
Level of care not adequate for Parkinson resident	Increasing care needs	Breaking down
Professed to be a dementia care center	Could not provide adequate care	Breaking down
ALF couldn't care for her anymore	Increasing care needs	Breaking down

Table 6

Changing Nature of Guilt in Family Caregiving

Feeling guilt *Breaking down*	Feeling more guilt *Shattering expectations*	Trying to alleviate guilt *Enduring the turmoil of transition*	Feeling guilt & grief *Facing the final loss*	Resolving the guilt Justifying the transition
Unspoken guilt: she could not let anybody know because she would just feel guilty that she wasn't able to handle daddy and get him in and out of the tub and all those things. It really does put a big stress on people**.** **Inflicted guilt:** Wait til somebody backs up a truck to your house and takes all your stuff. And from family members: you dumped grandma off? **Spoken guilt**: My house isn't user friendly. My house isn't user friendly and that is a GUILT I have always had. – Like I let me mom down or something, but it was what we had to do	**Spoken and observed guilt:** As she became more and more emaciated her family was dealing with a lot of guilt. "Had we put her in the right place from to begin with?" They were dealing with all of the questions along could they have done something different should they have done something different? **Inflicted guilt:** Because there won't be anybody to care for him. **So, it was interesting because my brother, on the other hand, put the guilt trip on my mother and said why are you going to do this? Why are you going to put him in the home and why are you going to do this?**	**Strategies to alleviate and monitoring care:** …families should be very watchful and advocate for their patients and …..and the family member is because of their guilt often will portray that on us and yell or call us names or say things about us and uh so it can be very um a big sounding board I guess you could say um for families who feel anger and guilt**…** **Trying to monitor to alleviate guilt:** once she moved to the SNF, it was it was just *he called everyday with complaint, He was miserable.* …I drove there everyday to see her and I don't know why, I just had to	**Guilt of giving permission and grief at the same time**: I cannot describe how I felt because my words were what ultimately helped her letting go. But at the time it happened, it almost felt like it was my fault Then of course I don't know, so I'm thinking well are they killing him? (morphine on hospice) **Not being present:** **Not being there at the time of death: that he knew that somebody was there (crying). I think that is part of the frustration and because you don't know**	**Looking back and trying to resolve:** Yes, the relief comes knowing they are no longer in pain. I don't think we have lingering guilt. We did the best we could. No lingering regret, she is finally at peace. She died on her birthday surrounding by the whole local family at the bedside. It was good closure for everyone to witness her peaceful passing. It took him the whole next year to get past feeling something else could have been done, but he's there now and says she probably would have gotten worse regardless of being moved or not.

To understand the circumstances and impact on families and hospice nurses of their experiences and perceptions regarding care transitions from home to ALF or SNF at the end of life.

Aim # 1: To identify and explore the experiences and perceptions of families regarding care transfers of their dying elderly at the end of life.

Sub-Aim #1: To identify and explore hospice nurses' experiences and perceptions of caring for the resident and their family during care transfers to and between home, ALF facilities and nursing homes at the EOL.

Sample (Purposive) N=14
Bereaved family members of residents who were receiving hospice care and were transferred to and between residential care facilities in last months of life

Sample (Purposive) N=13
Hospice nurses who have participated in care of a resident in ALF who was transferred from ALF to another health care facility at the EOL.

Data Collection
Face-to-face or telephone open-end unstructured interviews

Data Collection
Face-to-face or telephone open-ended unstructured interviews

Data Analysis
In Vivo Coding, Axial Coding Memo writing and constant comparison

Data Analysis
In Vivo Coding, Axial Coding, memos, Constant comparison

Emergent categories, Central Core Category Stages and Transitions Identified

Data Analysis
Theoretical codes Memo writing and constant comparison

Results of Aim 1, Sub-aim synthesized into the Living through the Care transitions of the dying elderly: the changing nature of guilt .in family caregiving.

Emergent categories
Central Core Category Stages and Transitions Identified

Actions and Roles of Hospice nurses and stage specific intervention strategies identified constant comparison
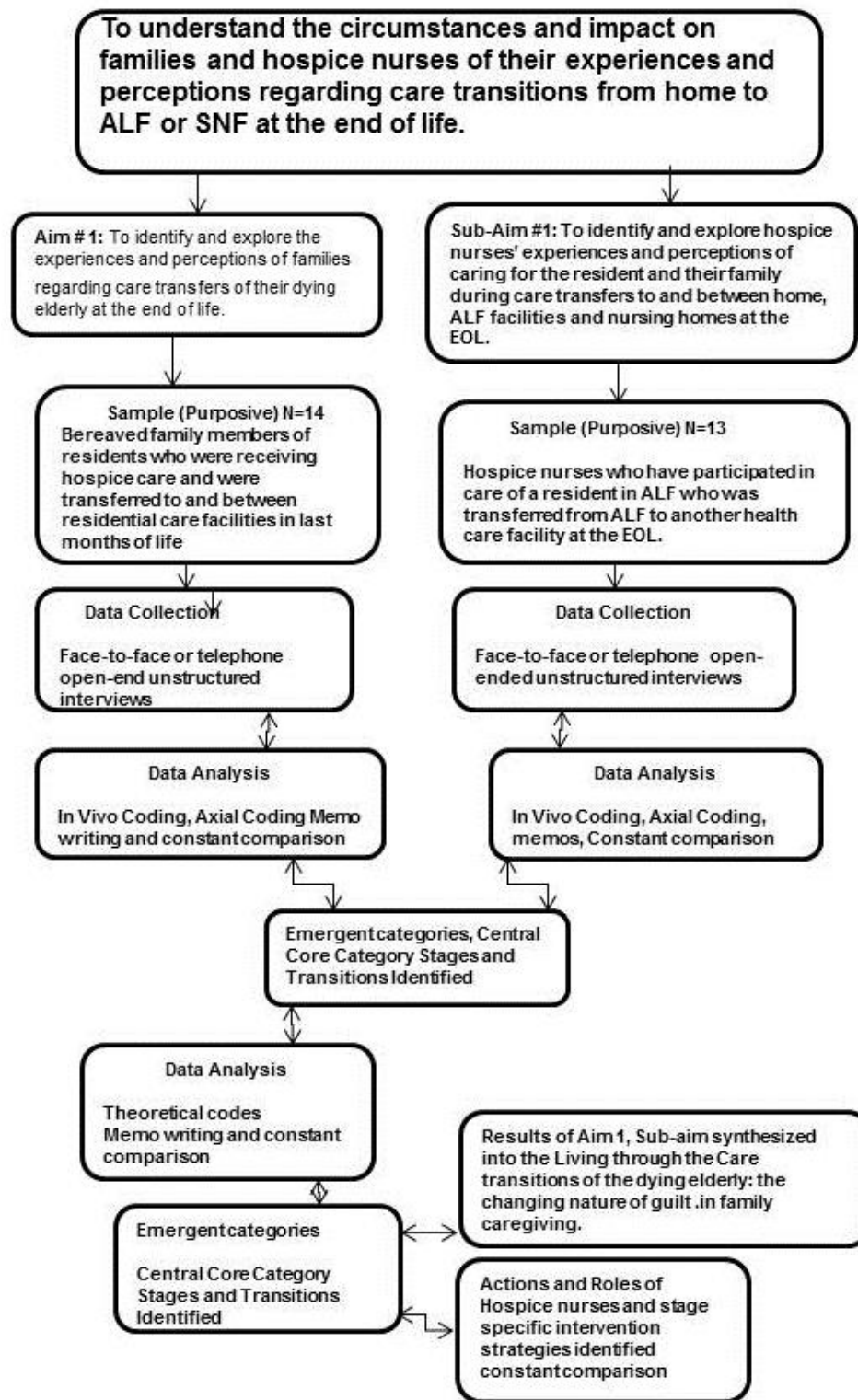
Figure 1. Study Design. .

CHAPTER 4

LIVING THOUGH CARE TRANSITIONS OF THE DYING ELDERLY:

THE CHANGING NATURE OF GUILT IN FAMILY CAREGIVERS

Support for dying elderly parents is ubiquitous in most societies, and is customarily provided by members of a family unit. Generally, families strive to provide care for aging parents or spouses in an effort to keep them in their homes as long as possible, to meet the desires of their relatives to remain at home until the end of life (Gruneir et al., 2007). Strong intergenerational bonds and feelings of responsibility, as well as societal norms and family expectations (Stuifbergen & Van Delden, 2011), can motivate adult children to provide care for elderly parents. In addition, they may have made promises that their loved ones will never need to move to a nursing home (NH). However, caregiving experiences can change over time due to complex issues of care breakdown including the increasing needs of the dying elderly as well as the physical, mental, and financial burdens of care (Blum & Sherman; 2010; Funk, Stajduhar, Toye, Aoun, Grande, & Tood, 2010; Stone & Clements, 2009).

When family members can no longer continue to provide the necessary care, the inevitable decision is made for a care transfer to an Assisted Living Facility (ALF) or a Nursing Home (NH). Some families choose an ALF, although when the need for nursing care increases, these needs may not met by the ALF, and residents must be transferred to

another institution. Many residents discharged from ALFs (i.e., 25% to 45%) are transitioned to a nursing home (Kane, Chan, & Kane, 2007). When they are transferred, it is generally to a skilled nursing facility (SNF) or NH, which is the institution they were trying to avoid with the move to an ALF. The transitions are burdensome for families, especially in a time of grief and pending loss. Moreover, nursing home placement has been shown to be an agonizing event which may cause reciprocal emotional suffering for the elderly and their family members along with the psychological burdens of guilt, regret, and loss for the family (Cheek & Ballantyne, 2001; Funk et al. 2010; Wilkes, Jackson, & Vallido, 2008).

The effects of nursing home placements have been well studied (Dellasega & Mastrian, 1995; Kellet, 1999; Penrod & Dellasega, 2001; Ryan, 2002; Strang, Koop, Dupuis-Blanchard, Nordstrom, & Thompson 2006;), but studies of the effects on families of the care transition to nursing homes at the end of life are limited. Care transitions of elderly family members from the home environment or ALFs to NHs at the end of life (EOL) may profoundly impact the quality of the dying process not only for the senescent individual, but for the family involved in planning and executing this transition (Mezey, Dubler, Mitty & Brody, 2002). Nonetheless, few researchers have evaluated family caregiver experiences during these care transition and their potential effects on bereavement. Patient- and family-centered outcomes of care are central to developing quality care models. To address the gap in the literature related to family-focused perspectives on care transitions of elderly relatives, the purpose of this study was to explore how families perceive such care transitions.

Background to the Study

The majority of frail older adults with chronic illnesses of advanced age are living in their own homes with support from either their adult children or from their spouse (Johnson & Weiner, 2006). An increasing number of older adults and their families are choosing ALFs for increasing care needs; however, families continue to provide physical, emotional, and financial support for members in ALFs (Gaugler & Kane, 2007; Port et al., 2005).

Older persons prefer to "age in place" in their own homes, and this concept has been extended to ALFs, where the environment is less restrictive than a nursing home (Ball et al., 2004). To successfully age in place means that a resident may "die in place," but with increasing age and frailty, care transitions can result in nursing home placement regardless of the origin. Therefore, the care transition itself may have an impact on the dying experience and how families experience a "peaceful" or "good" death for family members (Kehl, 2006). The resultant death experience may also have an impact on bereavement.

The attributes of a "good death" are highly individualized, changeable over time, and based on perspective and experience (Kehl, 2006). The Institute of Medicine (IOM) stated that a "decent or good death is 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" (IOM, 1997a, p. 3). Conversely, when persons are transferred to and between home and residential care facilities or NH, they and their families need to navigate a new system

and develop new relationships with new health professionals during a highly stressful time.

The number of family members providing care in the home for aging parents or spouses at the end of life is expected to increase (Penrod et al., 2011). As a result, this study will aid in understanding the impact on families of these care transitions on the dying experience and contribute to a continuing understanding of the components or attributes of a "good" death and its impact on the psychological health of families during bereavement.

<div align="center">Review of the Literature</div>

The experience of transferring to residential care, such as an Assisted Living Facility (ALF) or a Skilled Nursing Facility/Nursing Home (SNF/NH), has been shown to have burdensome consequences of stress, depression, financial burden, loss of personal possessions, and loss of personhood for the elderly (Mitty & Flores, 2008; Mollica & Jenkens, 2001). In many cases, both the older adult and their family are inclined to avoid institutionalization due to the long-held beliefs and fears about the stigma of a nursing home (Biedenharn & Normoyle, 1991). When home-based family [or ALF "home"] caregiving comes to an end, relocation to a higher level of care is sometimes required; patients are then transferred to NHs. Yet very little research exists on examining dual transitions, such as from home to ALF and then subsequently to SNF/NH. One qualitative study examined transitions to memory care units (MCU) within ALFs (Kelsey, Laditka, & Laditka, 2010). Results from that study indicated that the initial move to an ALF was less difficult for the adult children of residents to witness than it was for spouses; however, the second transition to the MCU was more traumatic for adult

children than for spouses because of limitations in decision-making (Kelsey, Laditka, &

Laditka, 2010). This dramatizes the many dimensions and changing perceptions of

family members during care transfers for elderly relatives.

Aging and Dying in Place

The concept of "aging and dying in place" is intriguing and may be more of a

marketing ploy than a reality for frail older adults living in ALFs. Research addressing

aging and dying in place in ALFs is limited. Ball et al. (2004) sought to gain an in-depth

understanding of the factors influencing the ability of residents to remain in ALFs. That

research highlighted the complexity of aging in place in ALFs and the need for a

coordinated effort among facilities, residents, and families to manage the inevitable

decline. Mitty (2004) described the regulatory and operational environment of ALFs with

regard to managing the older adult residents' decline by providing upstream palliative

care (UPC). The key finding of that study was that stakeholders did not support dying in

place as an outcome of aging in place in ALFs. This finding indicates a gap in care

continuity and an area where nursing should have a significant voice and role. Research

is needed to understand the impact of discontinuity on patients and their families.

Family Caregiving at the End of Life Stage

The predominant focus of literature regarding family caregiving at the end of life

surrounds care provided in the home along with transitions to end-stage caregiving roles

in the home environment (Andreshed, 2006; Funk et al., 2010; Kellett, 1999; Penrod,

2012; Waldrop et al., 2005). There is also a primary focus on cancer patients in this

literature. Funk et al. (2010) conducted a comprehensive review of qualitative research

on home-based family caregiving at the end of life, and identified research gaps such as contextual influences on family caregiving at the end of life that create challenges and identified a need to examine the processes for families.

One such study examining processes of caregiving through the end of life established a theory of "seeking normal" in the midst of the turmoil leading to the end of life (Penrod et al., 2012). However, despite this model's compelling evidence regarding the trauma experienced by familial caregivers, the contextual process of relocation at end of life was not included, and thus it is yet to be determined whether "seeking normal" is applicable in the care transition process.

Another concern identified in the literature was demonstrated when a feminist perspective examined daughters caring for dying parents and developed a theory of relinquishing that illuminated the process of turmoil in experiencing loss and adjusting to a new reality (Read & Wuest, 2007). Findings from this study emphasized the daughters' beliefs about filial responsibility and a sense of obligation to the dying parent. Read and Wuest (2007) stressed that unsupported family care must not be taken for granted at the cost of depleting daughters who are caring for dying elderly.

A gap exists in the literature regarding family caregivers at the end of life that includes health conditions and populations other than cancer patients. The science is weak regarding caregiving for older adults with various conditions.

Nursing Home Placement

The literature involving nursing home placement describes it as a life crisis involving stress and trauma for older adults and their families (Dellasega & Mastrian, 1995; King, Collins, Given, & Vredevoogd, 1991; Nolan & Dellasega, 2000; Waldrop &

Meeker, 2011). Davies (2005) explored relatives' experiences of the move to a nursing home to examine the extent to which data fit Meleis's middle-range theory of nursing transition, including the lack of emphasis in Meleis's theory on the reciprocal nature of relationships between nurses and family caregivers and the demonstrated need for further study. Davies (2005) posited that the theory of nursing transitions has applicability to supporting relatives in relocating a patient to a nursing home; however, the theory does not encompass the contributions relatives might have to a positive outcome, and requires further study.

Guilt

Although the transition to a nursing home has been shown to initially relieve the burden of care, feelings of relief were transient and the more common experience was continued feelings of loss, failure, and guilt (Gaugler, Anderson, Zarit, & Pearline, 2004; Kellet, 1999; Nolan & Dellesaga, 2000; Strang, Koop, Dupuis-Blanchard, Nordstrom & Thompson, 2006). Guilt is identified throughout the family caregiving literature, along with regret and depression (Davies & Nolan, 2004; Funk et al., 2010; Stone & Clements, 2009; Sussman & Dupuis, 2012). The concept of guilt has not been well studied. The majority of studies reviewed about guilt do not include large populations, and the concept has not been well defined (Li, Stroebe, Chan, & Chow, 2013). A review was conducted that determined there were two components to guilt: the affective and the cognitive.

These involved "moral transgression in which people believe their actions would contribute to negative outcomes and a sense of responsibility and painful feelings of remorse as part of the guilt (Tilghamnn-Osborne & Cole, 2010, p. 544).

The consequences of guilt include health outcomes and bereavement outcomes. Feelings of guilt and the associated feelings of anxiety and depression may have a significant impact on the well-being of family members (Li et al., 2012). Directly related to the dying process, there is an association between guilt and normal or complicated grief symptoms; however, its causal relationship has not been established through research (Akiyama et al., 2010; Field et al., 2000; Gamino et al., 2000; Mizota et al., 2006; Weinberg, 1994, 1995). In bereavement, guilt is considered an "emotional reaction in grieving when one has failed to live up to expectations to the deceased" (Lie et al., 2012, p. 156). If families are not able to meet the end-of-life care expectations of the dying elderly, the transition may impart feelings of guilt in bereavement.

<u>The Dying Experience</u>

Quality at the EOL includes two separate constructs: "quality of care" reflects the elements of a particular setting where the dying takes place, and "quality of dying" includes the symptom burden that might be influenced by the care. The patient and family provide important elements and voices for defining the quality of care and quality of dying, especially for the last place of care (Fowler, Coppola, & Teno, 1999).

Family perspectives of EOL care were examined at the last place patients had received care (Teno et al., 2004). The study revealed that institutionalized residents had many unmet needs for pain and symptom management, emotional support, physician communication, and respectful treatment. Family members were more likely to report a favorable dying experience when a person died at home with hospice services (Teno et al., 2004). Patient- and family-centered outcomes of care are central to developing quality

care models. Families and other informal caregivers are crucial to the care and coordination of health providers, as well as to the emotional support of older adults.

The coordination of care among the last places of care is considered a key component of quality of care. Studies on dying persons and their families have focused on finding ways to measure quality of care that were both patient-focused and family-centered (Teno, Casey, Welch, & Edgman-Levitan, 2001). That research has identified the key elements that constitute this type of care, which are (a) physical and emotional comfort, (b) shared decision-making; (c) focus on the individual, and (d) attending to the careers. Two key care processes run through those four elements: (a) informing and educating the family and (b) the coordination and continuity of care. No specific studies have evaluated the effect of various settings on families' perceptions of EOL care transitions (Teno et al., 2001).

Hospice care provided in the home to patients and their families is a critical component of ensuring that elderly patients can remain in their homes, but preferences change when symptoms are uncontrolled and when there is an inability to safely provide care in the home (Hurley, Strumpf, Barg, & Ersek (2014). Supporting family caregivers through continual transitions and moving them through "the unknown" (Ellington, Cloyes, Berry, Thomas, Reblin, & Clayton, 2013) is challenging for hospice nurses. When a care transfer takes place, the skills of a hospice nurse are invaluable in navigating systems as well as keeping families prepared for the constant changes, especially during the dying process.

Care Transitions

Many studies have explored transitions to end-stage caregiving; however, only four specifically examined the process of families' experiences of health care facility transitions at the end of life for those enrolled in hospice (Eagle & de Vries, 2005; Evans, Cutson, Steinhauser, Tulsky, 2006; Hurley, Strumpf, Barg, & Erserk, 2014; Waldrop & Meeker, 2011). Examining factors that precipitated untenable caregiving crises resolved by relocation (care transition), Waldrop and Meeker (2011) used crisis theory, a conceptual framework that delineates the experiences a person undergoes when confronted with a dilemma that seemingly impossible to resolve. The family caregivers in this study wanted their family member to remain at home and when this was not possible, it precipitated a crisis. In crisis theory, a resolution to the "unsolvable" problem – in this case a transition to a higher standard of caregiving – may yield both adaptive and maladaptive responses. The residents in that study were relocated to a hospice, providing them with a knowledgeable, professional staff and compassionate end-of-life care, assets that were central to the residents (as well as their relatives) who achieved adaptive or "settled" responses. Maladaptive responses were a result of unrealized expectations due to fears of overmedication for hospice pain and symptom management, as well as excess unhappiness from the newly transitioned resident (Waldrop & Meeker, 2011).

These hospice patients all transitioned to a hospice rather than a nursing home. Evans et al. (2006) included nursing homes, but only one of their 18 participants transitioned to a nursing home and six to hospitals, while the remaining 11 transitioned to hospice facilities. Findings from that study indicated families were satisfied during transfers if goals of care were clarified, treatment preferences were followed, care was

personalized, and the environment was pleasant (Evan et al., 2006) However, gaps remain in the literature that include ALFs and NHs.

Transitions have been defined as "the passage or movement from one stage, subject or place to another" (Merriam-Webster), and it has been proposed by Meleis's theory of nursing transitions that assisting people in managing life transitions is a central role for nursing (Meleis et al., 2000; Schumacher & Meleis, 1994). Making the transition to a nursing home is considered a traumatic experience for the entire family (Reed & Payton, 1996; Wright, 1998). Research examining transitions indicates that older adults and their families perceive these relocations as life crises and require understanding and effective management of the event (Brown & Furstenberg, 1992; Oleson & Shadlick, 1993). These studies were frameworks pertaining to nursing home entry and its crisis, but they did not examine the crisis surrounding the end of life.

A middle-range theory of transition in nursing described the vulnerability of families and patients related to these transition experiences (Meleis et al., 2000). Vulnerability was considered related to environmental conditions that expose individuals and families to potential problems with recovery or, in the case of caring for a dying loved one, delayed or unhealthy coping (Meleis, Sawyer, Im, Hilfinger Messias, & Schumacher, 2000) of the dying loved one and a disruption to bereavement.

The fact that people are living longer has led to an increase in the incidence of Alzheimer's disease and other dementias, which are a significant cause of institutionalization, disability, and mortality (Aaltonen, Rissanen, Forma, Raitanen, & Jylha, 2012). A recent study compared the number and timing of transitions between care settings among older people with and without dementia in the last 2 years of life, and the

most vulnerable times for transitions were in the last 3 months of life, when death became closer (Aaltonen et al., 2012). The rates were higher overall for those not living in residential facilities; however, toward the EOL, the rates were the same for both community-dwelling and residential care facility patients with dementia, when adjusted for age and gender.

Transfers in care from one health care setting to another are a matter of vital concern to both health care providers and policy makers, and above all, to patients and their families, due to the lack of continuity in care. These lead to medication errors, hospital readmissions, and added trauma. Maintaining a high standard of consistent and empathetic therapeutic care is both a fundamental component in the wellbeing of both patient and family members during the end of life process, as well as a core principle of the nursing profession.

In summary, family members as well as the dying elderly generally want to avoid institutionalization; however, circumstances override these desires even if a move was made to a residential care facility such as an ALF. The gap in care continuity as well as the disruption, stress, and trauma to both the family and the elderly person may impact the quality of the death as well as the bereavement and health outcomes of the family caregivers. Hospice care in the home is considered the most satisfying for family members; however, little is known regarding these care transitions for hospice patients and their families at the end of life.

Purpose

In this study, I examined the experiences of end-of-life care transitions to gain a deeper understanding of patients' and families' needs during these difficult times. Glaserian grounded theory was used in order to develop a model that identified the stages of the process to assist healthcare providers, particularly hospice nurses, in understanding and meeting the needs of patients and families at this time. Interviews encompassed the experiences of bereaved families whose dying elderly were transferred from home to and between residential care facilities and nursing homes.

Methods

The study was conducted using Glaserian grounded theory (Glaser, 1978) as an optimal method for understanding transitions in social processes. This method was very useful for understanding what was going on in a substantive area in order to explain and interpret the experience (Glaser, 1978). Inherent in this method was the ability to identify basic social processes and to describe phenomena, as well as the trajectory of change (Morse et al., 2009). This basic social process/psychological process or core category of Guilt explained a significant portion of the variance and provided an understanding of the circumstances and stages of the trajectory that families endure during times of transitions for their family members.

Sample and Procedures

Approval was obtained through the University of Utah Institutional Review Board on Human Subjects. Initially, sampling was purposive to identify participants who could yield the most information about the identified process in order to confirm the trajectory

through rich description of the stages as they are experienced (Morse, 2007). The inclusion criteria consisted of bereaved family members who experienced transitioning their dying elderly, primarily for those enrolled in hospice. Family members were recruited from a local College of Health Science that included ~85 faculty and staff. Two participants were recruited from that area. In addition, an advertisement was placed in the church bulletin of a community of 8,000 parish members, and 2 participants were recruited from that community. Two local hospice agencies agreed to contact family members, and most participants in the study were recruited from these agencies. As the emergent theory developed from interviews, theoretical sampling was used to recruit social workers and nurses from facilities to provide perspectives as well, along with families who were not enrolled in hospice.

A sample of 17 participants included 14 family members, 1 skilled nursing facility social worker, 1 assisted living facility nurse, and 1 hospice social worker. In addition, 3 family members were interviewed twice. Family members consisted of adult children including 10 daughters, 4 daughter-in-laws, and 1 son. Their ages ranged from 50-71, with the majority in the 56-60 range. Bereavement ranged from 6 months to 8 years with an average of 30 months. The social workers and ALF nurse were also female; ages ranged from 25-45. Shadowed data were obtained from family members and health care providers that increased the sample. At the end of the data collection period, when the model was developed, it was shared and discussed with 3 family members and additional data were collected to further define the theory to give a total of

23 interviews (*n*=23).[1]

<u>Data Collection</u>

      Interviews were conducted over a 12-month period, all of which were digitally

recorded. Interviews took place at the most convenient place for the participants, but if

the person could not meet, arrangements were made to conduct the interview over the

phone. At the time of the interview, the study was explained, and participants received

and signed a written consent explaining the risks and the benefits, the protection of

anonymity, and their ability to stop the interview at any time and withdraw from the

study. A cover letter consent form was developed to ensure consent from all participants,

including those interviewed by phone. The cover letter consent form was either mailed or

emailed by the principal investigator.[2]

      Interviews began with demographic questions, including age, relationship to the

deceased, the location of the transition, and length of time on hospice care. The

interviews were unstructured and began with a broad question asked as gently as

---

[1] Data included: One participant transitioned both her mother and her father and one participant transitioned his mother, father, and sister at different times. Two of the family members were not receiving hospice care, 1 of whom died just prior to enrollment in hospice care. Seven of the elderly transitioned from ALF to SNF/NH, 7 transitioned from home to SNF/NH, 2 transferred from home to ALF, and 1 relative came home to die.

[2] Three interviews were conducted in the participants' home, 3 were conducted in a restaurant, 2 were conducted at a healthcare facility, 1 was conducted via Skype, and 1 was conducted in the office of the researcher at the participant's request. The remaining 20 interviews were conducted via telephone.

possible: "Tell me about your [decedent]'s last month of life." The interviewer asked minimal questions without "leading" the participant, in order to obtain the participant's perspective. This approach increased the validity of the data (Corbin & Morse, 2003; Morse, 2012).

After initial interviews, data were transcribed verbatim by a research assistant. Transcripts were then listened to again and checked for accuracy and analyzed. As the understanding of the phenomenon became more evident, guided questions were used and were validated with other participants. ("Some people tell me…. Is this what it was like for you?"). In addition, as the theory developed, interview questions became more focused. For instance, as guilt and conflicted emotions became evident, these concepts were explored further in the interviews. For further validation, participants were called for a second interview to verify the findings.

Data Analysis

Data were analyzed inductively initially, line-by-line, using open coding in order to gain a better understanding of the data using the participants' own words. The analysis continued using memos and interpretive coding by asking analytic questions of the data. Axial coding identified specific properties and led to collapsing initial codes into categories and continuing to theorize the relationships among categories, which aided in the development of the core category of Guilt. The large categories initially developed included Elements of the Transition, Emotions of the Transitions, Decisions and Decision-making, Making Promises, Death Sentence, Caregiver Burden, Issues in the ALF, Feeling Guilty, and Hospice Care. Memos were made throughout, and the constant comparative method was used to compare incidents to incidents and categories to

categories, identifying similarities and differences in each level of analysis. This constant

comparison of these incidents and with incidents not yet coded began to generate the

theoretical properties of the category (Glaser & Strauss, 1967). Once the concepts were

identified into categories or classification of the concepts, generalizations were made

about the categories and explicated in a storyline (Eaves, 2001). For instance, Emotions

of the Transition was a large category; it was compared with the Feeling Guilty category.

Memos and theoretical codes began to abstract these into concepts asking: Is this

powerlessness or helplessness? If there is anger, who is angry?

The third type of coding in the analysis was selective coding, which further

theoretically identified the relationships among categories and further explicates the

storyline by determining the properties and dimensions within the categories. Initially,

the substantive codes conceptualized the area of research, whereas theoretical codes

conceptualized how the substantive codes related to each other as hypothesis and

integrated into the theory (Glaser, 1978). Once the categories were reduced to

subcategories and the characteristics, properties, and dimensions were delineated, the

core category was developed. For instances, Decision Making, Caregiver Burden and

Feeling Guilty were compared as the storyline was being explicated. Theoretical codes

of regret and duty or obligation were examined, and the dimensions of guilt were

delineated for type of guilt when this guilt was prevalent. Theoretical codes assisted in

explaining the types of Guilt (spoken, unspoken, observed, and inflicted) that were

prevalent (see Table 7). These theoretical codes gave a broad picture and a new

perspective (Glaser, 1978). Memoing involved notes written throughout the process of

data collection, concerning insights and addressed any preconceived assumptions and

bias. The codes and categories identified were compared to the existing literature for the emergent fit of the theory.

One aspect of the data that was considered in the analysis was the use of *shadowed data* (Morse, 2001). This entailed data reported by bereaved family members about their relative's perspectives and experiences as well as hospice nurses reports about families experiences "in general" along with particular instances without identifiers. Shadowed data increases the richness and scope of the data and therefore expedites the research as well as directed theoretical sampling (Morse, 2007).

Theoretical Saturation

Because in grounded theory, the sampling and analysis occur concurrently, theoretical saturation was reached when no new data emerged and all concepts and properties of the theory were well developed. After verification of the relationships between concepts and the linkages between them was completed, no additional data were needed. Once theoretical saturation was reached, differences in the trajectories were examined for negative cases. The results were integrated into a grounded theory of the basic social psychological processes occurring for family members during the care transfers of their dying elderly parent or spouse who was receiving hospice care.

Results

In this study, family members undertaking care transitions to and between home, ALF, and NH facilities for their dying elderly relatives experienced guilt throughout the process. This resulted from care expectations of the dying elderly and perceived familial obligations, as well as perceptions, fears, and avoidance of the nursing home

environment. In addition, many aspects surrounding the dying process elicited feelings of guilt. The theoretical model of *Living Through Care Transitions of the Dying Elderly: The Changing Nature of Guilt in Family Caregivers* provides a situation-specific framework for understanding the psychological process for families throughout the many stages. The core category of guilt is the central phenomenon experienced by the families, which escalates during the process, leading to reparation attempts to alleviate guilt, as well as trying to *resolve lingering guilt*. As shown in Figure 1, it is through these stages – Breaking Down; Shattering Expectations; Enduring Transition Turmoil; and Justifying the Transition – that families experienced guilt. Families incorporated strategies to *alleviate guilt*, including reparation attempts, as well as trying to *resolve lingering guilt*. The findings suggest that guilt may be mitigated by witnessing a "good death."

In trying to meet their needs and carry out their elderly parents' wishes for care, many families reported that the elderly person had expressed their fears, anxiety, and perceptions about nursing homes. Many elderly persons had given directions like "Don't ever put me in one of those places!" A nursing home was viewed as a place that stripped them of their dignity and where older adults were viewed as "guttering old fools" and would be "flushed like unwanted trash." As the families reflected upon their loved ones' perceptions, there was a consistent theme of the perception of a "death sentence" and a place they would surely "go to die" in an undignified manner. These conversations were said to be the center and the foundation for the feelings of failing to live up to their loved ones' expectations for care, and they resulted in guilt that was experienced throughout the process. This guilt increased once the inevitable decision was made.

Families felt obligated and willing to care for their dying elderly but were forced to make the difficult and frequently expeditious decision to relinquish that care due to the accelerating needs of the dying patient along with the immense strain on family members' physical, emotional, and financial resources (Waldrop & Meeker, 2011). This decision fractured relationships as the elderly experienced a tremendous sense of insecurity, and often they reminded family members of the promises and commitments made that had been broken. Families struggled with these feelings and internalized the guilt, which was sometimes spoken, unspoken or implied, as well as inflicted and observed. The following stages exemplify the Basic Social Psychological Process (BSPP) of the *Living Through Care Transitions of the Dying Elderly: The Changing Nature of Guilt in Family Caregivers.*

<u>Breaking Down</u>

Breaking down is the catalyst for the crisis-driven process of transitioning a family member at the end of life. Breaking down results from the deteriorated condition of the elderly parent and has the potential to co-occur with the breaking down of the caregivers' physical, emotional, or financial ability to maintain caregiving. The majority of adults in this study were living in their own homes or very close to an adult child prior to the care transfer event to a residential care setting. Family members were all adult children who were deeply committed to their parents care and felt overwhelmingly obligated and responsible for their care. As one daughter said, "I just think it's my job to take care of my mom and my dad…I would never not fulfill my obligation and responsibility unless I just couldn't." That attitude notwithstanding, this daughter, along with the rest of the family members who agreed to be interviewed, had arrived at a crisis

in care, a point in which they could no longer keep their elderly relative safe. For some, managing the care of both parents was an additional burden because they were forced to juggle both their physical and emotional needs while also continuing to meet the priorities in their own lives. In many instances, "mother was falling" or "she had left the stove on and it was getting too dangerous." Family members expressed the emotional turmoil, suffering, and angst in the process surrounding this necessary care transition from their homes to residential or NH care facilities.

Accelerating needs of the dying. The primary stressor is directly related to the elderly person's symptoms, including cognitive impairments and behavior problems (Blum & Sherman, 2010). This transitional event is part of the illness trajectory, signaling a need for increased care. Participants reported that breakdown occurred at a critical point, such as when their loved one's body and disease process could not be sustained by the same level of care any longer, and thus they could no longer be kept safe at home. One daughter described the experience of her father living at home with his elderly spouse prior to his care transition to a NH facility as one that resulted in guilt between witnessing the physical and emotional strain on her mother (and feeling like she should do more) and the devastation of transferring to a NH for her father, who she described as "a very independent guy. I think he would rather have gone to the woods and died himself rather than go to a nursing home." Thus, the *accelerating needs of the dying* were evident:

> ...In the last few weeks….. he had fallen and then, you know, it was just becoming too hard to do (care for him) at home … he became so incapacitated. Just to get from the bed to the bedside commode and it was beyond what people could do reasonably.

The woman's father was transitioned to a SNF/NH and died within 24 hours. The family experienced an immense amount of guilt and regret for not being able to care for him for one more day, feelings that in many ways eclipsed their grief and ability to process their loss.

A similar situation occurs in an ALF with the inevitable decline of the dying person, when the ALF cannot provide the needed care due to limited staffing and state regulations. For instance, if an elderly person becomes nonverbal and needs to take a medication, the regulations state the resident must be verbal. Similarly, if their skin begins to fail and a pressure ulcer develops, they need a higher level of care. As a result of limited staffing, a daughter whose mother was in a small ALF that advertised they provided memory care was stunned by the ALF requesting the transfer because her mother's behaviors were difficult for the staff:

> …and the people from the facility and I think basically they just told us they couldn't give her proper care and they just thought that we needed to take her where she could get better care.

The required transition was a move into an environment that the daughter and father felt was less home-like and was especially traumatic for her spouse. Hence, the daughter had to manage an additional transition of her mother and the resultant guilt; she also needed to support her father's anger and guilt.

The crisis of *breaking down* was reported to be evident to the elderly person as well. However, the expectation of the parent, as was in many cases, was that the care would be given by the adult child, which, when that was not possible, inflicted guilt:

> He told me that he knew he couldn't live there anymore, that he needed to go someplace else. He wanted to go to my home and I didn't want that and because I knew that it was going to be more than I could do. I work, and I could have quit I suppose, but I didn't want to do that.

Reaching their limits. Reaching their limits primarily involved caregiver fatigue and burden. Caregivers reached a point of breaking down when they "can't do it anymore" or the ALF was not able to manage the care and they were reaching their limits. Some of the demands on caregivers included managing medication, assisting with activities of daily living, and keeping them safe by assessing risk of falls, stairs, and toileting. The care also included much of the household management of cooking and cleaning, medical paperwork, and running errands.

The consequences of guilt associated with caregiving include health outcomes as well as bereavement outcomes. A daughter reported issues of how her own health had been impacted by many years of caregiving of her mother, and was given the advice from her physician; "The doctor said, either I put her in a care center or they prepare me for a long illness because I was getting so burned out." Another participant reported about her mother's care of her husband with cognitive impairment, "It actually took a visit to the doctor's office for her, with palpitations and all anxiety related from lack of sleep, etc., stress related, for us to realize how little sleep she was getting."

Conflicting responsibilities. Family members reported that the demands of caregiving led to *feelings of guilt* when there were conflicting responsibilities to the parent and to their own family. The ability to balance responsibilities, including caregiving, created guilt when the desired family-role outcomes did not meet the actual outcomes, as illustrated by this daughter:

> We continued to try to care for her but she became, she was wandering at night and she was falling and I'd go down in the morning to help dad pick her up because he couldn't get her up – it got to the point where I couldn't keep her safe –so I'm trying to hold down this full time job and it's pretty busy and I'm sleeping on the floor next to Mom to keep her safe.

Because of *conflicting responsibilities*, adult children/spouses are not able to achieve their desired outcome of keeping their relative from transferring to institutionalized care.

Exhausting resources. Along with *reaching their limits* with other responsibilities, the caregivers also exhausted their physical as well as financial resources to provide the needed care and keep them in their familiar environment. These situations also occur in ALFs when the plan of care becomes more complicated, increasing the rent. At times, residents move to a more economical ALF, which may lead to a decrease in the quality of the care. ALF care is not reimbursed by insurances, as illustrated by the following quotes by a daughter caring for her father with Alzheimer disease, "My total cost for my dad, more so than my mom, was two hundred and fifty thousand dollars out of my pocket. I'm grateful that they had money and we could afford this but the average person cannot do that."

While breaking down varies in duration and in tangible and intangible resources, in all instances, this stage ended at *making the forced decision*.

Forcing the decision. At this juncture, the decisions are forced because the situation has escalated to a crisis of safety for the elderly patient along with physical, emotional, or financial exhaustion for family members. For some, initially, there was denial and an avoidance of the inevitability of the situation. As one respondent put it, "Yeah and mom had …had Alzheimer's. I should have known she was going to do… and need it but it's my denial again. Yeah, I just denied it, denied it, denied it." Denial was a strategy used to cope with the significant amount of angst as family members juggle the emotions of guilt and regret. Making a decision that was explicitly unwanted or could

potentially cause their loved one harm was at the root of guilt. Choosing a facility was considered a burden for those who were not receiving hospice care initially because they were fearful of "choosing a bad one." Whereas hospice provided information regarding facilities to families and could ease this burden by supporting them during this decision-making time, nursing homes rarely did.

Regardless of the place of relocation (home to ALF, home to SNF, or ALF to SNF), many decisions still needed to be made. Deciding which facility would be appropriate was difficult for families. Some felt that an ALF was the answer to all their needs and the only transition they needed to make; then, when they had to make an additional move, it was overwhelming and traumatic. As the decisions needed to be made, the luxury of time was not on the side of the family; hence, the decisions are perceived as forced.

The transition situation was described as overwhelming responsibility, worry, and guilt:

> **…** and in hindsight I don't even know why, I couldn't even think. We've got money we probably could have done that for a month, but I didn't even think about it. Uh huh, yeah I couldn't do that. So you know I was probably my own worst enemy in that transition because I couldn't do the things I needed to do, I just couldn't do it. ……… Plus you know I didn't want to have to take responsibility for the care my mom was going to get, what if I chose a bad one?

In other instances, there were state regulation requirements in which the family did not have any choice or time in making the decisions and both the family member and the elderly parent were powerless over the circumstances of the transfer**:**

> The poor little thing--we take her out of familiar surroundings, which she wanted to be home anyway, but--familiar surroundings and have to move her along with my dad, who is now, at that point, 94, and had--he was still getting himself around pretty well, at that point, you know, but had had a stroke, and had to take her into this other facility and leave her there in the middle of the night……I just know

that we were told we had to get her out of there within an hour. And so we took her in there and left her that night.

 Forcing the decision ends the stage of *breaking down* and now the dreaded transfer needs to be made and the guilt accelerates as they enter the next stage of *shattering expectations* where the families are now *breaking a promise* made to their relative of "never putting them in a nursing home."

Shattering Expectations

Breaking promises. When a forced decision was made for care transfer of an elderly relative, it was often against the elderly relative's wishes and not what the family member had promised about care. Caregivers are then doubly dismayed because not only were they going against the will or wishes of their elderly parent, but the transfer was a "broken promise" made many years prior to this demanding stage of caregiving. Family members reported such things as, "I had promised her I'd never put her in a care center and that was very difficult for me to do so." This act of transferring her mothers' care increased her guilt because of familial expectations, causing her to feel more guilty.

Betraying a loved one. Family members reported their elderly parents felt betrayed and horrified to learn they would be living in such a place to mark the end of their lives, shattering their expectations of either remaining in their homes until the end of their lives, or being cared for by family members. Because of the broken promise, this feeling of betrayal often caused elderly parents to act out with verbal accusations or angry behavior, which inflicted guilt.

> We had always told her that she was never going to have to go, we would always take care of her. She had MS and it got to where you know we just couldn't take care of her…… it was very, very hard – you always tell her.. you know when you're a kid, you always say, mom, I'm always going to take care of you, you're

never going to have to do something like that and then you do….and she was very, very, very angry for a long time.

Fracturing of the relationship. Because of the undue circumstances of the care transfer, families were not able to fulfill their perceived (or society's perceived) obligation or duty to care. This broken commitment led to the fractioning of the caring relationship and also fractured the social norm of the obligation to care for aging parents which produced guilt, as well as shame, regret, grief, and loss.

Confounding these distressing circumstances and a reluctance to "send" their loved one to a nursing home were the perceptions of what happens at the nursing home, or what will become of the person being "put" there. The majority of family members reported their elderly family members thought residing in a nursing homes was a "shameful" experience that made older adults look like "guttering old fools that can't pass on any wisdom" and where they were abandoned. This loss of control is evident as with the deterioration and need for more care, the elderly felt like they were "carted off" and resulted in anger with this transition:

> She didn't want to go but she did. She kind of understood but she didn't. She was mad – there was the comment about "You just wait til somebody backs up a truck to your home and takes all your stuff.

This stage of *shattering expectations* ended when the families actually had to participate in "sending and putting" their loved ones in a nursing home. The language involved objectifies the elderly person, like language used for luggage or bad pets. This language also indicated the lack of choice for the elderly person and an act of wrongdoing by the adult child that led to shame, thereby increasing the adult child's guilt. This language marked the beginning of the next stage of *enduring the turmoil of the transition.*

Enduring the turmoil of transition. This stage of the process demonstrated the ways in which the families attempt to endure (Morse, 2011) this chaos and engage in activities to maintain control and steps to mend (*making amends*) and rectify fractured relationships and perceived wrongdoing as a way to try to alleviate guilt.

Relinquishing and monitoring care. Relinquishing physical caregiving was a strategy used by these families; however, they were still very much involved in "caring" through monitoring the care. After the transition was made, there was an adjustment in their caregiving roles which affected family members' identities. One strategy used by a majority of the participants to endure the *relinquishing* or fracturing of the care of their elderly loved one was to be vigilant in *monitoring* the care. This *monitoring* was one way of continuing the caregiving role, although the caregiver identity had changed.

The overwhelming sense of continued responsibility despite the *relinquishing* of care heightened family members' anxiety. The quality of the care at some of the facilities was distressing to relatives. One daughter described her mother had no ability to feed herself and without her family *monitoring* and feeding her, "she didn't eat….And so my aunt, her youngest sister, went over and fed her." And 1 participant believed, if "we had not been as watchful and intervening as we were I think she would have went downhill faster and passed away a year sooner."

Establishing trusting relationships. In order to relinquish the caregiving role, families tried *establishing trusting relationships*. This strategy of enduring this turmoil is central to the concern for a parent's welfare and attempts to alleviate guilt. Family members were using strategies for negotiating care in order to ensure the best care, which was demonstrated in this study by trying to develop trust with staff members. While

trusting the staff to provide the care their loved one needed would be essential in *alleviating guilt*, oftentimes family members were angry with staff in the facilities. Family members reported: "we kept a close eye on him," "my Dad he went over to visit her every day," and "trusting those people to take care of her correctly…not to abuse her or anything like that." One daughter reported that her 99-year-old father who was transitioned to an ALF asked, "How do you know that they are going to do the things that they say they are going to do? How do you know that?" The father's concern inflicted and heightened the guilt the daughter was already experiencing. A participant reported her father visited his wife every day and "had a kind of cadre of nursing assistants that he liked and he would encourage them to help mom and selected nurses that were there and understood for the most part the pain issues."

This constant vigilance is a strategy of *making amends* for the placement and *trying to alleviate the guilt* as illustrated in the following reported by an adult child:

> I felt like I had to go visit, I don't know if I really had to go visit every day, but I drove thirty miles every day to go visit because I felt bad for her being there all day by herself"……. And I felt guilty, every single day whether I went to see her; whether I called her, whether I had been twice um the guilt was a horrible thing.

Another strategy described as a way of enduring the turmoil was to normalize things: "you try to keep as many normal things as you can … we'd still have waffles every Sunday or whatever you know."

Witnessing the decline. As reported, the participants felt these moves could accelerate the dying process due to the quality of the care and the quality of patients' lives. Families had to endure this inevitable decline and often noticed it happening right away with the move: "he went downhill really fast once we got him there." These

observations led them believe that their decisions had caused the decline, and this added to their guilt.

Another participant's mother never spoke again after the placement, and each time she was transitioned even within the facility she would experience a decline. When one of her roommates died, it would precipitate yet another decline. There is a degree of uncertainty that both the residents and the families experience *witnessing the decline*. Being transitioned from one room to another means nothing looks familiar and the family felt this produced fear and was the cause of the decline.

> I don't think her transition would have been so detrimental if they had moved her things in. Like take her for a walk and move the items into her new room, cause she didn't have very many, just enough to make it familiar then walk her to that room, I don't think the transition would have been as hard.

Witnessing the decline of their loved ones was the reminder of the inevitability of the loss that was to come: "because with every time I knew that I was losing her more and more." This anticipatory grief is the beginning of the juncture of *waiting and watching* and leads to the stage of *facing the final loss*.

Facing the final loss. Throughout the process, both the elderly person and the family members are *facing loss*. Along with the loss and the guilt, grief arises because of the compounding losses for both the patient and the family. They suffered many losses: the loss of their home environment, whether that was their original home or their new-found ALF home, the loss of the breakdown of their bodies, the loss of independence, and the loss or fractioning of the caregiving relationship with their child or husband. Finally, for the elderly person, was the ultimate loss of their existence. Family members who received blame and bore the brunt of the anger from their dying parent at the same time experienced the grief of losing their parent or loved one. The losses were many and

varied and may have started with the onset of illness. For instance, as with parents with Alzheimer's disease, they said, "I had been losing him all along."

Letting go/saying goodbye. The strategy of *letting go* had to do with *giving permission*, *making treatment decisions,* and *being present*. Hospice was a critical part of the process as they assisted the families by educating them and letting them know what to expect as well as being the extra support they so needed during this difficult time. Repeatedly, the families described hospice as "a God send, and I don't know what I would have done without them. I really don't."

Giving permission. Being present for the dying process was considered for some a privilege but such a deep and profound loss at that same time. "I don't know that I ever felt more lost in my life than when I saw her take her last breath – she, it was gone." The privilege was described in helping them let go. Although families described this experience as profound, the *feeling of guilt* still permeated the process and was associated with giving them permission to go as "it almost felt like it was my fault."

Making treatment decisions. When medications were given by hospice to relieve pain or suffering, some families questioned their decisions by asking, "Are they killing him with the morphine?" One daughter reported trying to make treatment decisions made her feel "hopeless" and she had to dig deep to decide whether "to make someone comfortable or do you work to extend someone's life?" In this instance, guilt of those treatment decisions didn't seem to dissipate after her parent's death. She remarked:

> It was very troubling to me, and still is, I don't know that you ever know whether you make the right decisions for your loved ones.

This phase of *facing the final loss* ended with the participants reflecting on these events and *entering bereavement*, which included justifying the transition and *resolving lingering guilt,* which was characterized by *meaning making.*

Justifying the Transitions

Looking back. The participants reflected thoroughly on their experiences and because of the trauma and the turmoil, the experiences were remembered in detail. The majority looked back at their process and wanted to participate in the study in the hopes of helping others who may be entering this phase of their lives. In this stage of the process, hospice care was a very prominent topic for the families. The positive effects were indeed part of this reflection.

Meaning making. The release from the care transition crisis was evident when the families were able to reflect and valued the experience for the deep meaning within the experience. When the death was viewed as peaceful, participants said, "it was the best exit ever that I could have wished for" or "it was the best ending to a book ever." Hospice was considered "indispensable and irreplaceable." The participants reflected on these events and were able to see through their guilt, reporting "we did all we could." The descriptions of a "good death" in the literature include being present with the person at the time of death.

Regretting. Two participants were not able to be with their parents at the end and were still dealing with regret and *lingering guilt* of not being present at the time of death:

> So anyway I left and then that night, well it was one in the morning, they called me and told me he had passed. So I don't know if he really was with us or if I'm just hoping that he was--that he knew that somebody was there. (crying) I think that's part of the frustration and because you don't know.

Another participant dealt with regret from her last encounter with her mother and the lack of coaching from the hospice staff that precipitated *lingering guilt*. Her mother had Alzeheimers disease. She said:

> I startled her and she thought I was going to hit her which was the last experience I had with my mom. Her death was wrong….it was just wrong. I had called the hospice nurse after that. She reported that she was fine and she died within a few days and I wasn't there. The hospice nurse called me 24 hours later. It was awful.

> Making peace. The participants reflected on these events and were able to see through their guilt, reporting "we did all we could." The majority of the participants attended the death and being present with the person at the time of death is considered a component of a "good death" and is also described as a peaceful experience for families (Kehl, 2006).

This current study suggests that the view of the "good death" was the sentinel event that helps in *resolving lingering guilt*; however, this phase of the model needs further study as there were only 2 participants with negative death experiences, which may have impacted their guilt in bereavement.

Variations in the Course

As a comparison, when loved ones come home to die, many participants considered this the ideal in contrast to their experiences in nursing homes. One woman reported that she brought her mother home to die and that is when she discovered hospice care:

> She was thrilled, she got her wish, she got to die at home. And that was her wish. At that point, she didn't feel like a burden to anybody, she just thought, you know, this is awesome this is the way it should be. She got to look outside; all my garden was blooming so there was, you know, millions of flowers out there um it was a good death for her.

After her long experiences and suffering through the other phases of *breaking down*, *shattering expectations,* and *enduring the transitions* phases without the support of hospice, she described the impact of hospice in entering *facing the final loss*:

> Hospice saved my life I think. By the time I took my mom home… I couldn't function really, you know, yeah, I was working and trying to maintain everything, my house looked like heck but I didn't care, you know, it was just the camel that broke the… almost broke the back and then hospice came in and it was like wow it's okay, it's okay to call, you know, we called at 2:45 in the morning when my mom was starting to gurgle. Um because I couldn't handle that sound………… they just were the blanket I needed wrapped around me.

Family dynamics also play a critical role in this process. Some families reported issues that come into play in how involved they were in the process, especially conflicts with siblings and other family members that intensify during the end of life. Family dynamics were not fully explored in this study as the primary family member executing the transition's process was examined and other siblings were not interviewed and this needs to be further investigated.

As stated in the analysis, 2 of the participants had negative experiences with hospice. They felt hospice did not explain their role in the care and they could not recall any of the processes that most of the participants described as alleviating or easing the transitions. One daughter felt hospice did not support or coach her in the final dying phase. Another reported that she is "still angry" about her mother's falling out of her wheelchair in the care of a hospice aide.

Just as some of the particular family dynamics may influence the process, the particular nurse or hospice agency may also influences the process. How families experience these transitions are somewhat reflective of their own family dynamics as well as the quality of the hospice nurse and agency.

<u>Discussion</u>

A theoretical explanation of what family members experience when undertaking care transitions for their dying elderly relatives as the *Changing Nature of Guilt in Family Caregivers* can be of help to all involved with family caregivers. The situation-specific model of the psychological impact of guilt in care transitions conceptualized in this study contributes to nursing's understanding of the inherent emotional turmoil involved in transitions at the end of life. The study findings offer new insight into family caregivers' needs for support during transitions and have applications for nursing therapeutics as well as contributions to nursing research, practice, and health policy.

It is well established in the literature that nursing home placement of an elderly relative is associated with guilt, anger, despair, resentment, and general psychological distress for family members (Davies, 2001; Kellet, 1999; Nolan & Dellasega, 2000; Ryan & Scullion, 2001). Findings from those studies were congruent with this current study in that *feeling guilt* and *having to make a forced and negative choice* were reported, as well as the need to focus on family career support during the transition period (Kellett, 1999). However, this study contributes new knowledge to the focus on end-of-life care and reveals a further knowledge of the guilt and the potential impact on bereavement. These results also contribute to a beginning understanding of the issues surrounding residential care in ALFs.

<u>Guilt</u>

Generally, across all cultures in the United States, there is a common understanding and expectation that adult children are morally obligated to care for elderly parents (Theixos, 2013). Because of parental, societal, and moral expectation, the

resultant guilt carries with it the potential of shame which is distinguished from guilt as the public acknowledgement of the transgression (Harstade, Roxberg, Andershed, & Brunt, 2012). The adult children in this study exemplified this expectation and the consequence of guilt due to the inability to fulfill promises. A number of theories on filial obligations have been developed in recent years, and one in particular applicable to this study is 'filial obligations as an assumed promise' (Stuifbergen & Van Delden, 2011). The elderly parents felt they had a 'right' to the care they expected from their children because of the promises made to them of "never putting you in a nursing home." These unfulfilled expectations are at the route of the action of a perceived moral transgression and the feelings of remorse. The placement into a nursing home was often times against the wishes of the elderly person (albeit unavoidable) and led to the guilt of failed expectations.

The participants in this study similarly reported these two attributes of guilt throughout the transition process. Morally, people felt responsible and thereby thought their actions contributed to a negative outcome for their parents, which caused painful feelings of remorse as part of guilt (Tilghamnn-Osborne & Cole, 2010). Guilt arises from a perceived violation of a moral or social standard such as in the standard of familial obligations. Guilt is differentiated from other symptoms of psychological duress such as depression and anxiety (Glavin, Schuemn, & Reid, 2011); however, there is a positive relationship to anxiety and depression caused by guilt (Jones & Kugler, 1993).

Work-Family theoretical perspectives examined guilt when the ability to adequately attend to work and family role demands come into play (Glavin, Schieman, & Reid, 2011). The ability to balance responsibilities including caregiving creates guilt

when the desired family-role outcomes do not meet the actual outcomes. Women caregivers tend to have higher levels of guilt even after adjusting for work-family conflict and are more likely to have the perceived ability to give care related to their gender identity. This issue deserves further exploration as the responsibility falls mainly to women for the expectations of care of their aging parents as well as balancing work and their own family responsibilities.

In bereavement, guilt is considered an "emotional reaction in grieving when one has failed to live up to expectations of the deceased" (Lie et al., 2012, p. 156). These feelings of guilt and associated feelings of anxiety and depression may have a significant impact on the well-being of family members, especially women (Ferguson et al., 2000). More importantly, directly related to the dying process, there is association between guilt and normal or complicated grief symptoms; its causal relationship has not yet been established through research (Akiyama et al., 2010; Field et al., 2000; Gamino et al., 2000; Mizota et al., 2006; Weinberg, 1994, 1995).

Although the care transitions were often inevitable due to the physical, emotional, and financial break down, at times, elderly parents inflicted blame and guilt. The accepted blame often led to *making amends* during the period the elderly parent was living in the nursing home. Research demonstrates a correlation between self-blame and the actions of *making amends* with a favorable bereavement outcome (Weinberg, 1994).

Caregiver Burden

The findings from this study highlight the concerns and consequences of psychological distress and its impact on health, particularly women's health. Stone and Clements (2009) examined caregiver burden, which has been shown to cause physical

illnesses and psychological stress in caregivers and consequently lead to illness and even

a greater risk of mortality (Blum & Sherman, 2010). The majority of the study

participants in this study were women. Women are more likely to have the perceived

ability to give care because of their gender identity, and consequently tend to have higher

levels of guilt even after adjusting for work-family conflict (Glavin, Schieman, & Reid,

2011). The societal and familial norms or expectations of daughters caring for their

parents have demonstrated that women often reach a breaking point in providing care (as

cited in Wuest & Read, 2007) because of multiple roles. In this study, participants felt

their *conflicting responsibilities* contributed to the care transition when adult

children/spouses were not able to achieve the desired outcome of keeping their relatives

at home.

Transitions to Nursing Homes

Findings from the Kehl and colleagues (2010) study that examined the challenges

facing families at the end of life in three settings were consistent with this current study.

The researchers found that placement-related regrets, bearing witness to suffering

(*witnessing the decline*), and the absence of trust in care providers (*establishing trusting*

relationships) were prevalent for families whose relatives were in skilled nursing

facilities/NH. These consistent results contribute to the knowledge of families

experiences at the end of life and emphasize the importance of creating ways to further

understanding these issues such as the situation-specific model.

The psychological distress families faced during the stage of *Enduring the*

Turmoil of the Care Transfer was evident as they suppressed their emotions and

developed strategies to manage the situation (Morse, 2010). The family caregivers are

also experiencing a change in role, relationships, and patterns of behavior (Davis, 2005).

The distressing emotions of the fractured caregiving relationship led families to strategies

of frequent visiting and vigilance while *monitoring and relinquishing the care*.

Relinquishing is considered a strategy of sustaining loss while continuing to care for a

family member (Wuest, 2000). Vigilance is described by Read and Wuest (2007) as a

surveillance strategy for maintaining some sense of control because of the disruption to

the family unit. These actions and strategies of enduring are attempts to alleviate some of

the guilt by *making amends*. According to the literature, there tends to be more

associated guilt if there are troubled predeath relationships characterized by frustration

and dissatisfaction (Li et al., 2013). A daughter demonstrated this concern when she did

not have the opportunity to make amends with her mother because their last interaction

was troubled by her mother's perception (due to Alzeheimers disease) that her daughter's

was about to cause her physical harm. Because she felt she did not have adequate

guidance during the actively dying phase, she did not have an opportunity to make

amends and thus was unable to resolve *lingering guilt*.

The outcome of the transitions was either negative resulting in the psychological

distress of *lingering guilt* or positive indicators such as meaning-making when observing

a "good death," which is consistent with other studies (Waldrop et al., 2005) including

the positive effects of bereaved family members of their caregiving experiences as

"making sense of the event and finding benefit in the experience" (Davis, Nolen-

Hocsema, & Larson 1998, p. 561). In addition, similar findings from Sinding and

Aronson (2003) suggest that family caregivers invoke idioms such as "they did

everything they could" (p. 103). These authors suggest this is a way to manage the regret

and responsibility as well as to reconcile the expected "good death" with the death that was observed. Findings from this study suggest reconciling and justifying transitions occur as a result of hospice care and their ability to support and inform family's surrounding the dying process.

Several studies have suggested that less intensive guilt has been found among family members for whom the deceased had a "good ending," such as passing away peacefully, with all wishes carried out, and adequate care (Akiyama et al., 2010; Jonasson et al., 2011; Surkan et al., 2006; Ylitalo, Valdimarsdottir, Onelov, Dickman, & Steineck, 2008). These claims were supported in this current study by the family members. Family members felt the hospice nurses provided them the knowledge about the end-of-life process, kept their loved ones comfortable, and allowed them some relief and acceptance that aided in *resolving the lingering guilt*.

Hospice Care

Hospice care can assist families in navigating the complexities of these life events through the interdisciplinary care team. Shield et al. (2010) revealed that hospice services in the nursing home seemed to share the burden of monitoring and advocacy. Only 2 family members did not have hospice care for their relatives and had no formal health care provider support. In addition, 2 of the participants had negative experiences with hospice. The findings from this study offer hospice care providers' valuable information to assist families in managing the end-of-life crisis. Research indicates that there is greater family satisfaction when hospice is involved, especially in skilled nursing facilities (Andershed, 2006; Baer & Hanson, 2000; Teno et al., 2004). Most of the study participants receiving hospice care during times of care transition found it to be

extremely helpful during this tumultuous time as a support for the families. The hospice

nurses' interventions, especially during *facing the final loss,* were critical to family

members and had positive effects on the family caregiver's ability to resolve any

lingering guilt; however, further inquiry is needed. Meleis's theory of nursing transitions

proposed that assisting people in managing life transitions is a central role for nursing

(Meleis et al., 2000; Schumacher & Meleis, 1994). However, if families are not enrolled

in hospice care, they may not have direct access to health care providers during the care

transfer.

Results from this study revealed that hospice care contributed to an adaptive

bereavement response. A study conducted by Waldrop and Meeker (2011) is the only

similar study to this current research that specifically included hospice patients. The

conceptual framework for their work included crisis theory, and they discovered similar

findings of adaptive or maladaptive resolutions to the crisis; however, those authors only

examined the resolution to the relocation and not the entirety of the death experience. In

that particular study, the relocation was to a hospice house rather than a nursing home,

which may in fact be the reason the majority of the participants had an adaptive

resolution to the relocation (Waldrop & Meeker, 2011). Demonstrating these positive

effects is critical to improving access to hospice care to assist families during this specific

type of transition.

Care Transitions

Similar to Davies' (2005) examination of Meleis' theory of nursing transitions

and relatives' experiences of nursing home entry, findings of this study concur there is a

need to support relatives during this period. The participants in this current study

demonstrated that guilt is a pattern of response and a process indicator for family members. The therapeutics of hospice nurses' understanding and support of older people and family caregivers help to achieve the outcome indicators of a "good death." Clearly, this conceptualization of outcome indicators in transitions theory at the end of life needs further investigation to understand the complexity of the patterns of response and its outcome indicators.

There is a lack of studies related to interventions for family caregivers of patients in end-of-life care transitions. This study revealed an understanding of psychological impact on family members that will aid in the development of stage-specific interventions. These interventions can then be tested to create evidence of care on family caregiver outcomes and determine if there are any long-term benefits, especially in bereavement, for caregivers. Also, further research is needed to understand and adapt interventions with culturally diverse populations (McMillan, 2005). These needed and important investigations will give voice to the needs of family caregivers and evidence for healthcare practices and policy decisions.

Limitations of the Study

The limitations of this study include its focus on those older adults who were receiving hospice care; further development and testing with end-of-life situations for those who were not receiving hospice care are called for to help understand whether these supportive interventions change any of the conceptual variations of the study. For instance, the analysis of the final phase could be further developed to consider processes and develop an understanding of complicated grief and guilt. In addition, the variations due to family dynamics and guilt need to be further explored. There are a considerable

number of complexities that may impact the changing nature and resolution of guilt in family caregivers.

Conclusions

Conceptualizing guilt in transitions at the end of life is useful to developing an understanding of the potential impact on bereavement through further description of families' experiences of a "good death." Results of this study suggest that nursing actions/therapeutics in hospice care support the transition process and effect the bereavement and potentially health outcomes for family caregivers, especially for women. Linking this current model to Meleis' middle-range theory of transitions has implications for including end of life as a context in its application for understanding transitions as well as family caregivers' needs. Nursing therapeutics is seen to influence all phases of transitions in Meleis' theory and in this study, hospice nurses' actions appear to have an impact on *resolving guilt*, especially when preparing them for the dying event, and may impact health and bereavement outcomes of family caregivers. Thus, the utilization of hospice services, or even transitional care nurses trained in end-of-life care, during transitions could be further evaluated. Considering the instances of caring for frail elderly relatives is expected to increase, the effects on family caregiver's needs warrant further study. Families will live with the memories of these final experiences of their dying elderly's life (Marco, Buderer, & Thom, 2005). Therefore, developing a theoretical understanding about the specific psychological processes families undergo during these transitions can guide hospice and palliative care professionals to incorporate stage-specific interventions as they assist families to navigate these complex stages at the end of life.

Furthermore, providing care to elderly relatives is becoming increasingly recognized as a critical issue because of changes in health care systems, as well as an ever-increasing aging population (Kita & Keiichi, 2011; Penrod & Dellesaga, 2001). Supporting family caregivers in the home will continue to be at the forefront of policy concerns because of the ever-increasing elderly population along with the change toward outpatient care as family caregivers are indispensable to the healthcare system (Hebert & Schulz, 2006). In addition, the dramatic increase in residential care/ALF indicates a shift in where older adults reside and the resultant challenges indicated in these findings need further clarification as research concerning ALFs is in its infancy (Kane, Chan, & Kane 2007). Frailty of advanced age and increasing medical issues are of concern because these facilities are not equipped to provide nursing care, thus a resultant transition. Without a direct link to the healthcare system such that palliative care or hospice care provides, families can be overwhelmed during these crisis. Increasing access to palliative care or hospice care providers with an interdisciplinary team approach is essential not only for providing patient-centered and family-focused care. Giving voices to these families and contributing to the body of knowledge may influence policies for vulnerable older adults and their families.

Table 7. Dimensions of Guilt

Stages in the Changing Nature of Guilt	Participant Comments	Types of Manifesting Guilt
Feeling Guilty	**Interviewee**: .She could let anybody know because she would just feel guilty that she wasn't able to handle daddy and get him in and out of the tub and all those things. It really does put a big stress on people**.**	**Unspoken Guilt:** A sense of responsibility and duty to her husband. Letting someone know would induce the public form of Guilt which is considered to be shame.
	Interviewee: My house isn't user friendly and this is a Guilt I have always had – like I let my mom down.	**Inflicted Guilt**: Unfulfilled promises. Obligations or expectation.
	Interviewee: "Wait til somebody backs up a truck to your house and takes all your stuff.	**Spoken Guilt**: These words induced feelings of wrong-doing. As well as a responsibility and duty.
	Interviewee: As she became more and more emaciated her family was dealing with a lot of guilt….. "Had we put her in the right place from to begin with?" They were dealing with all of the questions along could they have done something different should they have done something different?	**Spoken, observed and inflicted Guilt:** At this stage, they had either made the decision or were making the decision for placement, the idea of lack of quality and potential harm adds additional feelings of Guilt.
	Interviewee: So it was interesting… my bother.. put the guilt trip on my mother and said why are you going to do this? Why are you going to put him in the home?	**Inflicting: Sister witnessed her sibling questioning as causing guilt.**
Trying to Alleviate Guilt	**Interviewee:** be very watchful and advocate for their patients and …..and the family member is, because of their guilt, often will portray that on us and yell or call us names or say things about us and uh so it can be very… a big sounding board I guess you could say.. for families who feel anger and guilt	**Unspoken but observed in strategies to alleviate** Guilt is more latent than expressed… demonstrated in the behavior and actions to alleviate the Guilt.
	Interviewee: once she moved to the SNF, it was just. -He called every day with complaint. He was miserable… just miserable.	
	Interviewee: I drove 30 miles each way to visit every day. I don't know why I visited every day, I just had to.	
Feeling Guilt and Grief	**Interviewee:** I cannot describe how I felt because my words were what ultimately helped her letting go. But at the time it happened, it almost felt lke it was my fault	**Spoken Guilt and grief:** The help received from the hospice nurses and the observation of a peaceful death – was helpful in resolving guilt.
Resolving guilt:	**Interviewee:** Yes, the relief comes knowing they are no longer in pain. I don't think we have lingering guilt. We did the best we could.	**Justifying the transition by the good experience in the end of life for most participants**
	Interviewee: No Lingering regret, she is finally at peace. She died on her birthday surrounding by the whole local family at the bedside. It was good closure for everyone to witness her peaceful passing	
	Interviewee:: It took him the whole next year to get past feeling something else could have been done, but he's there now and says she probably would have gotten worse regardless of being moved or not.	**Indicates a process of justification.**

Breaking Down

Accelerating needs of the dying
Reaching their limits
Conflicting responsibilities
Exhausting resources

Feeling guilty

Forcing the Decision

Shattering Expectations

Breaking promises
Betraying loved ones
Fractioning of relationships

Feeling more guilt

Sending/ Putting

Enduring the Turmoil of the Transition

Relinquishing and monitoring the care
Establishing trusting relationships
Witnessing the decline

Trying to make amends to alleviate guilt

Waiting & Watching

Facing the Final Loss

Letting go/saying goodbye
Giving permission
Making treatment decisions

Feeling guilt & grief

Entering bereav- ment

Justifying the Care Transition

Looking back
Meaning making
Regretting
Making peace

Resolving lingering guilt

Figure 2. Living Through Care Transitions of the Dying Elderly: The Changing Nature of Guilt in Family Caregiver

CHAPTER 5

ACTIONS OF HOSPICE NURSES TO ALLEVIATE GUILT IN FAMILY

CARGIVING DURING CARE TRANSITIONS AT THE END OF LIFE[3]

Families provide the majority of caregiving for frail older adults with chronic

illness and comorbidities (Johnson & Weiner, 2014). These older adults and their families

may be vulnerable due to the rapidly changing health care delivery system. If admitted to

the hospital, they have a shortened length of stay and are often discharged quickly,

necessitating managing their illness at home. As a result, family caregiving (FG) is

reaching epic proportions with increased concerns of caregiver stress and poor health

outcomes for the caregivers (Funk et al., 2010). The significant physical and mental

health effects on caregivers as well as the financial burdens of care are well documented

(Caron & Bowers, 2003; Funk et al., 2010; Waldrop & Meeker 2011).   FGs are

managing a multitude of issues, including physical and functional decline (including

assistance with bathing and toileting), accelerating needs of their dying loved one, along

with limited resources to pay for additional care in the home.[3] These burdens also include

a reciprocal suffering that may occur as a result of caring for terminally ill family

members and the associated changes in the caregiver's and care recipient's quality of life

(Caron & Bowers, 2003; Sherman, 1998; Waldrop & Meeker 2011).

---

[3] This article will be submitted to the Journal of Hospice and Palliative Nursing and
followed manuscript guidelines.

When the elderly persons are at the end of their life, and they meet the qualifying criteria, hospice care can provide a much needed resource for families and patients in the home. Most people prefer to die at home, and hospice care in the home has been rapidly increasing with 66 % of the 1.6 million patients being served in a private residence (National Hospice and Palliative Care Organization (NHPCO), 2013). For some, remaining in their home is not an option due to the many shifting dynamics of the accelerating needs of the dying, the conflicting responsibilities of the caregivers, and the exhausting of financial resources to support caregiving in the home (Blum & Sherman, 2010; Funk et al., 2010; Stone & Clements, 2009).

When home-based family caregiving comes to an end, the dying elderly are transitioned to either an Assisted Living Facility (ALF) or to a Nursing Home (NH) to provide the care (and some are transitioned to inpatient hospice facilities if one is available). Relocating a family member to a residential or institutional care facility is considered a life crisis for the elderly and their family members (Dellasega & Mastrian 1995; Nolan & Dellasega, 2000; Waldrop & Meeker 2011). The transition to institutionalized care has not been well studied for those elderly receiving hospice care, and little is known about the perceptions of families undergoing this process or how hospice nurses interventions affect these transitions. The purpose of this research was to describe the actions of the hospice nurses in response to the psychological processes that families experience when their dying elderly are transferred to and between home, ALF, and NH facilities. The role of the hospice nurses in response to family's experiences has implications for practice and future research.

Literature Review

Hospice and palliative care recognized and focused on the patient/caregiver dyad when the demands of family caregiving and the high levels of burden became evident Blum & Sherman, 2010).   Although FGs play a critical role in the effectiveness of the home hospice model (Cloyes et al., 2014), research has shown FGs are reluctant to address their own spiritual, psychosocial, and care needs (Cloyes et al., 2014; Kutner, Kilbourne, & Costernaro, 2009). Yet, less is known regarding the role of hospice nurses supporting family caregiving needs.   A recent study (Cloyes et al., 2014) compared hospice nurses and former FGs regarding the ideal outcomes of support for FGs compared to actual practice. Findings highlighted the challenges of accomplishing family-centered care and recommended interventions to improve education of nurses, and the hospice team, based on the experiences of caregivers (Cloyes et al., 2014).

Ellington and colleagues (2013) examined the challenges hospice nurses face in supporting FGs during home visits and elucidated the professional development needs for home hospice nurses as well as mentoring programs.   The key concepts from that study revealed the skill level needed to address caregiver needs, the unique setting of family-centered and home care, the role of communication, and the recognition that "family providing care for a dying member is a family that is in continual transition" (Ellington, et al., p. 1016).

Research on caregiving at the end of life is focused primarily on the home setting and also specifically in cancer patients. Few studies have been conducted involving hospice care provided in ALFs, although The National Center for Assisted Living (NCAL) reports that 65% of all ALFs allow hospice services (National Center for

Assisted Living, 2010).   ALF administrators support hospice involvement when a resident is terminally ill (Caffrey et al., 2012; Dixon, Fortner, & Travis, 2002). If the resident's medical and functional needs are beyond what a facility can manage to keep them safe, a nursing home or hospital is often considered. The NCAL 2000 survey (Caffrey et al., 2012) reported that 33% of ALF residents were sent to a nursing home facility. Hospice nurses play a significant role in providing EOL care in ALF and research is limited; however, one study interviewing ALF staff and hospice nurses concluded strong teamwork, good communication, and use of multiple sources of knowledge, along with shared expectations about managing problems, contributed to accomplishing the resident's goal to die "at home" and in comfort (Cartwright, Miller, & Volpin, 2009).

Hurley et al. (2014) explicated a process that could affect a seamless transfer: development of a plan for future needs, identification of triggers signaling increasing needs for care, and navigation through succeeding phases of care. Rather than responding to a crisis, this plan would be developed with the patient, family, and interdisciplinary hospice team (IDT) and suggests that place of death can be negotiated through these processes.   Although remaining in their home is still a preference, the hospice setting is far more palatable to families than the nursing home setting, yet these preferences have not been fully explored.

As part of a larger study to explore and provide an understanding of how bereaved families and hospice nurses experienced and perceived care transitions from home to ALF or NHs for their dying elderly family member enrolled in hospice care, the first aim of that study was to develop a theoretical understanding of how the family is affected by

the transfer of the dying elderly to and between facilities A theoretical model of the stages of these transitions was developed as "*living through care transitions for the dying elderly: the changing nature of guilt in family caregivers,*" using grounded theory methods. From this method, a basic social/psychological process was evident as the families go through the various phases of guilt at each stage of the process and was presented in a previous manuscript (K. Martz, unpublished manuscript, 2014). The stages began with 1) breaking down 2) shattering expectations, 3) enduring the turmoil of the transition, 4) facing the final loss, and 5) trying to resolve lingering guilt. When the family members witnessed what they considered a "good death," the guilt dissipated and the experience had meaning (K. Martz, unpublished manuscript, 2014). Another aim was to describe the perception and experiences of hospices nurses of families' experiences and needs during transitions of their dying elderly that will be described in this article. The hospice nurses observed the guilt and distress in families and intervened in the process (Figure 2). Hospice was central to providing comforting actions to assist in alleviating the suffering of families and their loved ones in all stages (K. Martz, unpublished manuscript, 2014).

The purpose of the following study is to develop an understanding of the crucial role hospice nursing care provides in these care transitions. The findings will provide hospice and palliative care health care professionals a better understanding of the psychological processes during each stage and situation specific interventions for end-of-life transitions.

<u>Methods</u>

The study was conducted using Glaserian grounded theory (Glaser & Strauss, 1978) as an optimal method for understanding transitions in social processes. The basic psychological and social processes provide an understanding of the circumstances and stages of the trajectory that families endured during times of transitions and the roles and actions of the hospice nurses are explicated during each phase.

Sampling for the hospice nurses was purposive. 13 hospice nurses were recruited from two hospice agencies as well as the local Hospice and Palliative Nurses Association, along with snowball sampling. Theoretical sampling included interviews with 1 hospice social worker, 1 Skilled Nursing Facility/Nursing Home social worker, as well as 1 Assisted Living Facility nurse (*n*=16 participants) and 4 hospices nurses received follow up phone calls and (*n*=20 interviews). To expedite the research and direct theoretical sampling, hospice nurses reported data about their observation of family member's experiences "in general" as well as particular instances, without identifiers. The use of *shadowed data* (Morse, 2001) increases the researchers understanding of the generality of these data, the segmentation of the sample, and the identification of categories.

A cover letter consent was given or sent via email to the participants with a verbal agreement to participate. Approval was obtained through the University of Utah Institutional Review Board on Human Subjects.

<u>Data Collection</u>

The interviews took place primarily over the telephone; however four were conducted face-to-face. Interviewing took place over 12 months and all interviews were digitally recorded. The majority of the interviews lasted 60 to 90 minutes. Interviews

began with demographic questions, including age, educational background, as well as where the majority of the transitions took place. After the initial interviews, data were transcribed verbatim, read and corrected by the principal investigator, and analyzed. As the understanding of the phenomenon developed, guided questions were used to validate response of other participants ("Some nurses and families tell me… what experiences have you seen with?"). At the end of data collection, a theoretical group interview was conducted with 2 hospice nurses to share and discuss the proposed model and also to collect data in areas that were thin and to determine areas in which they disagreed with the model.

<u>Data Analysis</u>

Interviews were transcribed verbatim by a research assistant, de-identified, read, and corrected as needed by the Principal Investigator. Using the basic psychological process of *"Living Through Care Transitions for the Dying Elderly: The Changing Nature of Guilt in Family Caregiving"* (K. Martz, unpublished manuscript, 2014), as a scaffold, I explored the reported interactions of hospice nurses at each phase of the process. Data were analyzed inductively with the first level of coding using open coding (Glaser & Strauss, 1978) in order to gain a better understanding of the data using the participants own words. The analysis continued using memos and interpretive coding by asking analytic questions of the data. The next coding involved axial coding that identified specific properties and led to collapsing initial codes into categories while simultaneously continuing to theorize the relationships among categories, aiding in the development of the core category. Memos were made throughout the coding process

comparing incidents to incidents and categories to categories and identifying similarities and differences in each level of analysis.

The third type of coding used was selective coding, which further theoretically identified the relationships among categories. The development of theoretical codes gave a broad picture and new perspective of abstraction into an integrated theory (Glaser & Holton, 2004).

Results

The results include the demographic characteristics as well as presenting the actions of hospice nurses throughout the care transitions illuminating and discussing stage-specific actions and educational implications.

Demographics

Hospice nurses include 12 females and 1 male and ranged in age from 32-65 with the mean age of 49 years old. Years of experience ranged from 1-35 years with the average 9 years and 9 months. Education included 3 Associated Degree RNs, 4 Baccalaureate degree RNs, 1 Masters prepared Hospice Director, 1 in a Master's program, and 3 Nurse Practitioners. The hospice nurses reported on a variety of transition experiences, including home to ALF, home to SNF/NH, ALF to ALF, ALF to SNF/NH, and SNF/NH to home.

Actions of Hospice Nurses to Alleviate Guilt in Family Caregivers:
 Supporting the Transition

To alleviate means to "make (suffering, deficiency, or a problem) less severe" (Oxford Dictionary retrieved http://www.oxforddictionaries.com/definition, 2014).   One of the roles of a hospice nurse is that of a supportive presence and their actions with family members can help to alleviate the suffering and the guilt of these transitions, thus making it feel less severe. The patient/caregiver is the "unit of care" as hospice nursing is intervening with the suffering of the dyad. The hospice nurses observed the distress in families, and the resulting guilt that changed during the process (Figure 1).

Breaking Down

In the first stage of *Breaking Down*, FGs were experiencing an emerging crisis. The elderly relatives in the study were primarily parents of adult children, and either they or their living situation was breaking down as the elderly parent was in need of a level of care that could no longer be sustained in the home. Hospice nurses observed the variety of triggers that influence this emerging crisis. In some cases, it was the dying person's increasing needs and in other cases or simultaneously, the caregiver's were reaching their limits due to many conflicting responsibilities and as a result could no longer continue to manage the care. In addition, the elderly relative who had already transitioned to an Assisted Living Facility (ALF) for care experienced a break down in the facilities ability to manage the increasing care needs as well, due to staffing and state regulations.

The *support* provided by hospice nurses in easing these transitions and easing the burden of guilt were evident when they assessed the needs and the impact on both the resident and the FG and recognized the psychological burdens of care as the situation

emerged to a crisis point. The hospice nurse's primary concern was the safety of the patient; however, recognizing and *assessing* when safety was compromised by the heavy burden on the caregiver was critical.

First, the nurses and the hospice team identified the needs and triggers of the pending crisis for the individual patients and their family. The patients' safety may be jeopardized either at home or in a facility and at the same time, they are acknowledging the patient's wishes:

> There's times when the team really struggles because we know that the patient really, really wants to be there. And we have to be the ones to facilitate (the move) because it borders some point on the regulations of abuse, neglect, and exploitation. And so it becomes complicated.

Shattering Expectations

Once that assessment was made, educating the family on the physical needs of their elderly, and validating all the care the family member has already provided was essential to the therapeutic intervention and alleviating the psychological burden of guilt by validating them through the unavoidable agonizing decision due to the broken promises to their parent of "never needing to go to a nursing home." As one nurse reports:

> So it's still emotional. Emotional stages because of the guilt and feeling like…
> And at the same time, we have to help them work though that, and instruct them,
> yes you made that promise when the person was up and caring for themself and
> was able to do things. Now when they're not able to do that and it's really hard
> to take care of them. The transfer. They have no other options.

Managing the plan becomes the priority for the nurses because they do not want the family to undergo dual transitions, such as to ALF and subsequently a SNF. This required skills of juxtaposing advocating for patient and families of remaining in their "home" with anticipating and *managing* issues in the next place of care in order to

prevent another transition. This assessment becomes a team effort as they work with the

patient's wishes, families' burdens, the safety of the patient, and collaborating with the

hospice team in developing a plan based on that assessment.

As part of the Interdisciplinary Team (IDT), the hospice social worker evaluates

the situation based on her knowledge of systems and levels of care that families would

not necessarily be aware of without hospice services. The skilled assessment the social

worker provides, along with her ability to negotiate with families, is a comprehensive

view of the situation and is described by a hospice social worker *managing* these issues:

> Yes, we try to be very proactive. So that, if people need to go to an ALF--they wouldn't have to move again. Because, yes, it's very traumatic. Although I know that hospice is now in SNFs and they bring hospice in as consultants. Most of us – our heart is to help people stay at home. ….. If they had to go to a higher level of care than the family could provide at home, we really tried to make it just one transition. Ok now, can they stay here until they die? And really get that planned ahead and we would really try to get the family on board with that, and get them to understand that it totally depends on which facility you go to.

Regardless of the nature of the transition, the unavoidable decision to move to

any residential or institutional care setting invoked feelings of guilt as reported by

families and confirmed by hospice nurses. For the elderly who are already in an ALF, the

specific state regulations can result in families having to make a forced decision; the

hospice nurses use the role of communication in *navigating* and *negotiating* with systems

to advocate for their client.   One nurse reports:

> So what we know from a hospice nursing standpoint is that most ALFs cannot care for patients through end of life due to the strict ALF regulations and the specifics of an RN having to administer medications when a patient is in a comatose state, or the fact that the patient might be a two-person transfer, or, the list goes on and on. So when families are placing a patient in an ALF, they're not of that mindset of looking 6 months, a year down the road if my loved on declines.

Educational issues were identified because some nurses may not be aware of all the nuances of *navigating* these systems. ALFs are relatively new environments for the delivery hospice services, and some nurses may not have received information about the specific regulatory issues that are interpreted differently by different facilities:

> I think even the hospice company could have more education. I'm not even sure our company was even aware of the policy when this came up; I know that they had another patient in this facility. I think as a hospice nurse that's another thing that we have to plan ahead for in order to help our patients. I'm not sure whether the social workers know all of the details of what the regulations are when a patient is in a facility. So just a lot more planning, education, projecting.

The nurses reported that they "try not to voice those frustrations to the families" and therefore, along with *navigating* these systems, they are *supporting* the family's decisions and wishes trying to keep their relative from having to transfer from their "home." However, if it was a matter of safety for their patient, they were *advocating* for the patient to be transferred to where they could accomplish the care needs.

FGs often need direction during these times of crisis and hospice provided them information in order to make informed choices by *enabling* and *empowering* when making the often forced decision for nursing home placement. The nurses empowered FGs to visit a variety of facilities and investigate to make their own determination of the transition, recognizing this as "a burden to the family at a time that is very emotional… trying to get their affairs in order."

Enduring the Turmoil of the Transition

Hospice nurses were essential in helping families *endure the turmoil of the transition*, because along with relinquishing the care of their dying elderly to the facility, they had to become familiar with a new group of caregivers and circumstances and learn how to continue to monitor their family member's care. At the same time, hospice nurses

reported they as the health care providers also needed to relinquish the care and have additional responsibilities with formal caregivers. Once again the nurses had to *negotiate* care plans with another set of caregivers.

The hospice nurses provided an extra layer of supportive care, consistency, and knowledge that families reported helped them on this continuum of care (K. Martz, unpublished manuscript, 2014). The one person they recognized and who knew their loved one and their family was the hospice nurse. Nurses and social workers enabled the family by *encouraging* them to visit at different times of the day to assist in *monitoring* the care. And, the hospice social worker was crucial in arranging all of the transition needs for the family ahead of time.

During this stage of the transition, while trying to maintain the familial bonds and demands of continuing care, hospice nurses confirmed that many families reported the increase in guilt as they tried to make amends and adjust to the fractured relationship by monitoring, visiting, overseeing the care, while trying to establish trusting relationships with staff. The hospice nurses are an extra support and assist families in *monitoring* care and *advocating* for their care. And many nurses reported being watchful*:* "We actually stepped up our visits to make sure that they were doing what they said they were going to do." And at the same time the nurses were *encouraging* families to alleviate their guilt and worry*:* "…. and I encouraged them to go in different times of the day to get a feel for what's happening." For example, one describes *monitoring* and *advocating* for a vulnerable adult who did not have local family and addressed the specific concerns of caring of a patient residing in an ALF:

> …..they don't have the staff there that are able to take these people to the toilet or toilet them. My personal experience where I walked in and I had a patient that

had three levels of Depends on. And so I was quite upset with that. And this was in an ALF. And I was very upset and went down and got their nurse and brought her back up and said that this is totally not okay to do this - and I understand why it is being done, but that doesn't mean that it is correct. I will not tolerate this for my patient. If I come back and see this again, I said, I will have to push for other avenues.

Facing the Final Loss

When reaching the fourth stage of the dying process and facing the final loss, the

nurses' are *coaching* through the dying process. *Coaching* is described as a crucial

therapeutic intervention in the nurse patient relationship in which one of the main tasks is

to interpret unfamiliar diagnostic and treatments, which occur as the family members are

watching the dying process. In the first aim of the study, bereaved family members

described these actions as critical:

> ….you keep asking yourself how much longer is it going to be? Is she showing signs that it is going to be a day or is it going to be two weeks, or six months, or whatever? And "Nancy" (hospice nurse) was very helpful in being able to describe what was going on with my mother emotionally and physically - and also very calming in the whole process too, because you can't help but be very upset about it. It was my experience in knowing how much she helped me; it encouraged me to recommend her for a friend of mine which I can guarantee you I never would have done had I not known that this is something that they really need. I knew I needed it, but I didn't know it till afterwards.

This daughter reported about her experience in the final phase with the hospice nurse and

describes the therapeutic, trusting, caring relationship that needs to be established in order

for the *coaching* to be successful:

> So this person, you really – and I think that's important because this is a position you need to trust someone in. And because they're going to be telling you things that you may not feel comfortable with. So anyway, being able to work one-on-one with that person, knowing that person – unless there is….an emergency happens and she couldn't come – knowing that she was going to be there and who she was and how.

Moreover, when this critical intervention was not available to families, this negative case

demonstrates how painful the experience can be without adequate *coaching* of a hospice

nurse:

> I had read articles about if hospice is really…if hospice is killing people basically, you know with the morphine. My youngest son told me one day, he says mom they've got to be killing him with that morphine, and I said well they're telling me that it's a very, very slight, the lowest, lowest dose. He says if you put that into a 99 year old man that weighs as much as he does now, who is just skin and bones, you're just going to kill him. Then of course I don't know, so I'm thinking well are they killing him? But do you let him just live in pain? And, and…what do you do? [crying] I think they maybe could have been more, you know sit down and tell us this is what you need to expect kind of thing.

Justifying in the Transition

The last stage of the psychological process described trying to resolve lingering

guilt as families reflected back on the experiences. In the sample of a bereaved family in

the first aim of this study, the bereavement and the guilt were affected by the perception

of a "good death." This related to the skills and the actions of the hospice nurses;

particularly surrounding *coaching* during the dying process; however, all variations in the

course were not fully examined. For example, a few nurses discussed some patients who

were able to transition back to a family member's home to die and that was reported as a

very positive experience as well for the patient and the family.

> I know sometimes people have gotten to be too much for ALFs that the families have then taken them home to die, which is incredibly….a real gift. But the families and the patient know it is for a short time and they can do that. That's been a very special time for some people – to go home.

> One participant was both a family member and a hospice nurse (became a hospice

nurse after her experiences of a "good" death for her mother). She experienced a number

of transitions for both of her parents and suffered guilt as a result of the quality of the

experiences her mother had in the nursing home. She opted to fulfill her mother's wishes and brought her home to die with hospice care. She reported:

> I think it makes all those hoops and horrible days and pain, grief, suffering, and thoughts that I had actually diminish. I think having a good death, if you will, um made it all worthwhile.

The family dynamics need further study in relation to transitions. Nurses reported there were differences between families who were united in their decision-making to transition as well as those who were not united, yet there were not enough data to evaluate this particular aspect of care. However, as one hospice administrator noted, "good deaths" are the exemplar and expected due to the extensive knowledge and philosophy of hospice care; however, there is an emotional labor and a kind of trauma for the hospice nurses when they are not able to accommodate a good death due to existential suffering.

Many of the skills and actions described by the hospice nurses are inherently the skills they would use when caring for any patient regardless of the place; however, the specific knowledge of the variety of residential care facilities and issues and concerns in NH, along with the family's particular stresses and guilt during transitions at the end of life highlights the therapeutic effects of hospice nurses with family caregivers. In this study, the skills of the nurses have an increased nuance when home hospice care is ending and the care is transferred. The expert skills of c*oaching*, combining therapeutic *support,* and education during the dying process resulted in what families perceived as a "good death" and have a potential to impact any lingering guilt in the bereavement process.

Discussion and Implications

Findings from hospice nurses regarding the needs of families and the crucial role hospice care plays in these transitions will assist hospice providers in creating more focused interventions and identify educational implications. The stage-specific interventions outlined in Table 8 provide a resource for the essential work of hospice care: alleviating the suffering of the dying person and maintaining the integrity of the family. *Supporting* families was central to alleviating the suffering of the psychological processes of guilt in family members (Figure 3).

The tensions and complexities involved in hospice nurse support of FGs at home have not been emphasized in education and training of hospice nurses (Ellington et al., 2013). There are many skills needed to manage a patient on home hospice care; however, there are specific skills needed to effectively work with families and support them during these difficult transitions. Findings of this grounded theory study further delineate the complexities of family caregiving and extend this work into another dimension of transitioning from the home to a residential facility.

There were some variations in actions based on the education level of the nurses, and those with less education described the actions of referring to social work for care of the families having difficulties with the transitions. The hospice nurses with further education described their actions and interventions more thoroughly and demonstrated their knowledge of collaborative practice. Further investigation would be needed to determine if there are differences related to education levels; however, a recent study indicated the psychosocial support was better handled by other members of the hospice

team (Cloyes et al., 2014) because the management of physical symptoms is more important for the nurse.

Transporting traditional hospice care that was originally designed to be delivered in a person's home environment to these institutional settings is fraught with barriers, challenges, and opportunities (Dixon, Fortner, & Travis, 2002). One of the skills demonstrated by the hospice nurses in this study was in the role of communication. Navigating complex systems such as the variety of ALFs along with the differing ways in which they interpret state regulations necessitated the need for nurses to have a good understanding of these systems in order to negotiate and develop care plans that would facilitate remaining in the ALF. Cartwright and colleagues (2009) described the specific skills of strong teamwork, good communication, and the use of multiple sources of knowledge when trying to facilitate the resident to remain in their ALF home; however, these skills are identified in this current study as essential during care transitions to SNF as well.

The communication skills of *negotiating* with facility managers and staff to create a plan of care included asking the facility to apply for a waiver of consent in order to remain in the facility for residents who were imminently dying. According to the nurses, this would entail more frequent visits, enlisting family members' support, and working with the interdisciplinary team and volunteers. This highlights the specific education of the roles of communication which involves *negotiating* and conflict management with individuals, families, and systems. Hospice nurses' recognition of the psychological distress of guilt associated with relocating their dying elderly is critical. The

consequences of ineffectively recognizing the variety of sources of conflict and its

consequences may diminish support for patient and or the FG (Boek & Kramer, 2012).

Family perspectives on end-of-life care highlight the need for increased education

of health care staff on the dying process (Jackson et al., 2012), and hospice nurses have

the skills and knowledge to meet these needs. The specific skill of *coaching* provided

support and information during the dying process and is considered an expert skill

combined with formal education and clinical experience (Benner, 2000). This is

consistent with another study on the complexities of supporting family caregivers in

which leaders in hospice revealed that home hospice nursing requires advanced clinical

skills and ongoing education (Ellington et al., 2013). The hospice nurses in this study

did not discuss the specifics of educating and informing families about the dying process;

however, family members indicated the importance of knowing what to expect and

receiving information about treatment decision was critical to their emotional health (K.

Martz, unpublished manuscript, 2014), which is consistent with the literature (Jackson et

al., 2012). The bereaved families interviewed reflected on their loss and emphasized that

having this support during this difficult time was as one daughter described "like having a

blanket wrapped around me."

The literature on caregivers' perspective of nursing home placement reported

families need direct assistance with the admission process and also to help in negotiating

the process (Penrod & Dellasega, 2001). Attending to the family carers was identified as

one of the key elements that constitute patient-focused and family-centered quality care

(Teno, Casey, Welch, & Edgman-Levitan, 2001). As identified by those authors, the

coordination of care among the last places of care is considered a key component of

quality of care. Patient- and family-centered outcomes of care are central to developing quality care models as well as specific interventions. Families and other informal caregivers are crucial to understanding the needs for the care and coordination provided by hospice, as well as understanding the emotional support of these older adults and their families during difficult transitions in care. The majority of hospice patients are receiving care in their homes prior to these transitions in care; therefore, understanding the caregivers' needs during the process, in addition to the hospice patient, is critical to supporting family caregivers (Ellington et al., 2013).

Limitations

The sample for this study did not include chaplaincy as part of the hospice team. In future research, the sample must be expanded to include chaplains as well as additional hospice administrators, nurse practitioners, and social workers and all members of the team. While this limits the scope of the findings of this study, findings remain important for nursing. The study may also be replicated and further examine the educational implications. In addition, there is a need to evaluate critical skills of hospice nurses for managing family dynamics. These were not evaluated in this study. Finally, including or comparing transitions at the end of life for those transitioned to inpatient hospice or hospitals could also be examined in the future.

Implications and Conclusion

The insights included in this study provide necessary information of caring for family members to be included in continuing education for nurses as well as the hospice team surrounding transitions for patients and their families. The reciprocal nature of

suffering in both the patient and family caregivers during terminal illness may be increased during residential care transitions, and emphasizes the need for identification of stage-specific assessment and interventions.   These implications inform the focus of hospice care for agencies and will assist them in supporting family caregivers. Moreover, they will assist in the education of families undergoing painful, guilt-filled transitions. Further research is needed to test nursing interventions provided for the psychological care of families, and such care may have an impact on bereavement outcomes. These crises of relocation have implications for policy on care coordination for frail older adults and their family members as well as a need for increased access to hospice services.

Table 8. Stage-specific educational implications for hospice providers

| Family Member	Hospice Nurse Actions	Educational Implications
Stage 1 Breaking Down – *feeling guilty* – Making a forced decision	*Supporting, Assessing, Managing Navigating Negotiating*	-Incorporate training and education of the psychological processes for families during this phase of transition or potential transition. -Assessing families on effects of caregiver burden on health, along with safety needs of the patient. -Education and training of the residential care facilities and regulations for navigating and negotiating care.
Stage 2 Shattering Expectations –*feeling more guilt* Sending/Putting loved one in a nursing home.	*Enabling/encouraging Advocating Monitoring Alleviating Supporting*	-Validate feelings of guilt and discussing the expected reality versus the actual reality. -Provide guidance and encourage families to visit nursing homes to determine their preferences. -Educate on the prevention of transitioning by advocating for the appropriate level of care for their patient. -Supporting decision-making process – allowing time to express feeling. -Assessing the need for supportive services such as social work, chaplaincy, or professional therapist.
Stage 3 Enduring the Turmoil of Transition – **Making amends for the guilt** Witness and watching the decline	*Navigating Advocating Monitoring Supporting*	-Education on the process of making amends to alleviate the guilt while witnessing and watching the decline. -Training on monitoring the care given at the facilities and also encouraging families to monitor to alleviate their worry and suffering. -Education on conflict management between facilities and families.
Stage 4 Facing the final loss – **Dealing with guilt and grief** Entering bereavement	*Coaching and Supporting*	-Provides coaching (education) of what to expect during the dying process. -Providing information about treatment decisions. -Being present to family as much as possible. -Supports family through anticipatory grief.
Stage 5 Justifying the transition- **Resolving lingering guilt**	*Bereavement services provided by hospice agency – no specific hospice actions.*	-Perceived good death has implications for bereavement. - Issues affecting bereavement.
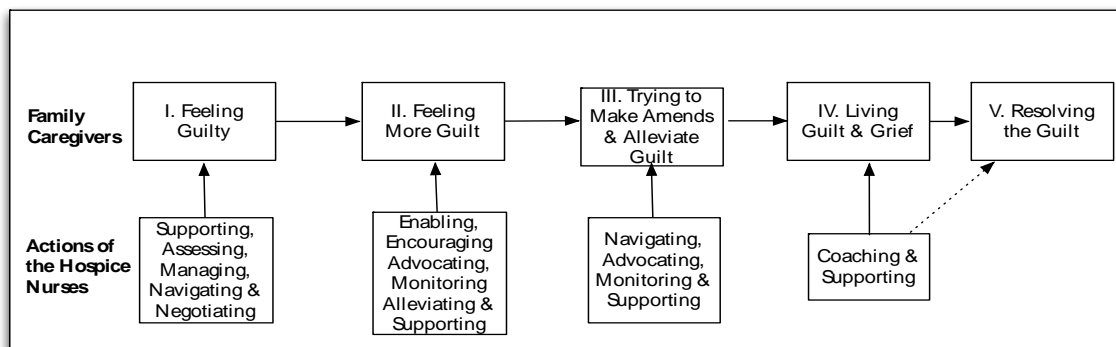
Figure 3: Actions of Hospice Nurses to Alleviate Guilt in Family Caregivers: Supporting the Transition

CHAPTER 6

DISCUSSION AND CONCLUSION

The purpose of this grounded theory study was to explore the circumstances and interpret the impact on families' and hospice nurses' perceptions and experiences of residential care transitions at the EOL for older adults enrolled in hospice. The conclusions from this study answered the research questions, and the findings explicated a situation-specific model of *Living Through Care Transitions of the Dying Elderly: The Changing Nature of Guilt in Family Caregivers*. The stages of these transitions included: 1) Breaking Down 2) Shattering Expectations 3) Enduring the Turmoil of Transition 4) Facing the Final Loss 5) Justifying the Transition. Throughout these stages, the core category of guilt emerged and its changing nature of escalation, attempts at reparation, and eventual resolution or lingering effect. The roles and actions of the hospices nurses were described in the process in each phase as they worked toward *alleviating suffering* in both the patients and their relatives. Following is a discussion of the development of the grounded theory findings and the core category concept of guilt and the conclusions drawn from this research.

The Grounded Theory Discovery and Related Literature

In research using Glaserian grounded theory, the review of related literature occurs in stages as processes are identified and as the theory develops. The original

directive from Glaser (1967) is to develop the understanding without any preconceived direction from the literature. However, it is now recommended that researchers sensitize themselves to the literature in the substantive area (Glaser, 2004; Stern & Porr, 2011) and this review of the literature is also a part of the research proposal. The substantive area of interest in this project was transitions of hospice patients from Assisted Living Facilities (ALF) to Nursing Homes at the end of life.   The lack of research, or gaps in knowledge surrounding this topic area, were described in Background and Significance of ALF and EOL in ALF literature in Chapter 2 and this review assisted in the development of the initial research question. For a theoretical understanding, the literature surrounding transitions was also examined.   Meleis' Nursing Transitions theory was shown to lack components that would be relevant to transitions at the end of life (Meleis, Sawyer, Im, Hilfinger Messias, & Schumacher, 2000). End-stage caregiving theories were also examined and very little evidence existed on end-stage caregiving for the elderly enrolled in hospice care, with the exceptions of a large percentage of studies focused primarily on caregiving for cancer patients (Funk et al., 2010). However, there were four studies examining transitions for hospice patients at the end of life, although primarily transitioning to inpatient hospice facilities (Eagle & de Vries, 2005; Evans, Cutson, Steinhauser, & Tulsky, 2006; Hurley, Strumpf, Barg, & Erserk, 2014; Waldrop & Meeker, 2011). This applied to considerably different environments than a skilled nursing facility/nursing home.

Once the research commenced, the literature formed a backdrop to gain a theoretical understanding of emerging categories and concepts, in order to develop theoretical sensitivity to the emerging concepts. At the same time throughout the

interviews and analysis, I was cautioned to resist the urge of making theoretical leaps without attending to an in-depth analysis. Theoretical leaps have the potential to limit conceptual understanding and truncate theory development.

A valuable tool for conceptual analysis was participation in doctoral seminars. Discussions centered on analysis and interpretive coding by developing theoretical memos. As discussed in these sessions, the use of interpretive coding enabled examining and analyzing the data to "get behind the data" to reach the inductively derived concepts. This process gave theoretical direction, along with building concepts and increasing theoretical sensitivity. A common mistake occurs when novice researchers are led by the literature instead of data. Validity is lost when conceptual leaps are made rather than seeking the interpretation as it emerges from the data (J. Morse, personal communication, March 2014). Once the concept was fully evaluated, linkages between concepts were examined. At this time, I then proceeded to the literature.

During the final stage of analysis, the literature was examined to corroborate key findings and linkages to the existing literature of the developed theory as a final verification. This literature was cited throughout the interpretation of the results of other in the research articles, and validates the findings as well as examined the differences in the known science.

The emergent theory of the *Changing Nature of Guilt in Family Caregivers* began with the development of an understanding of the psychological impact of facilitating the transitions on family caregivers. Family members described the ways in which the suffering and trauma of the relocation caused guilt. An analysis of the concept of guilt was needed to verify findings.

The Concept of Guilt

The development of an understanding of guilt began with psychological theories related to moral behavior and the formation of psychological symptoms (Tangney, 1996). A literature review conducted to understand the definition of guilt in bereavement revealed there is no agreement on defining guilt among psychologists (Li et al., 2014). A major review identified 23 psychological definitions of guilt as well as 25 measurements of guilt and concluded guilt involved two components: feelings and actions. The *feelings* were of remorse due to the belief there was an *action* or moral transgression that contributed to negative outcomes (as cited in Li et al., 2014). Similarly in grief, guilt is a painful reaction in grieving to the "recognition of having failed to live up to one's own inner standards and expectations in relationship to the deceased and/or the death" (Lie et al., 2014, p. 166).

According to the early work of Tangrey, Miller, and Barlow (1996), the main function of guilt stems from the central need to belong. As this relates to this current study, the caregiving role was ending and the relationship was fractured. The action of transitioning their dying relative to a nursing home was in fact a realization they were not living up to their own inner standards or relationship expectations in which their relative belonged to the family, and resulted in the feeling of guilt.

As a member of a family unit, the obligation to care or the duty to care (Wuest & Hodgins, 2011) is a perceived expectation and most of the adults in this current study wanted to honor their parents or spouses wishes of being cared for at home by family members. According to Wuest and Hodgkins (2011), the legitimacy of the demand to care involves the degree of dependency of the person needing the care and especially

when the potential risk of harm is high. It also increases when no other options are available. In a study examining daughters caring for dying parents, the potential benefit associated with caregiving was the mitigation of anticipated guilt was associated with refusal to care (Wuest & Hodgkins, 2011). Although the majority of participants in my current study did not refuse to care for their dying parent, the act of transitioning their family member to a nursing home was viewed by the participants as a violation of this duty to care and responsibility for and to their loved one.

The transition to a nursing home may be viewed as a potential or real threat to the human bond, or fracturing of the caring relationship, as is experienced in grief. Guilt is the emotional reaction that serves to foster reparative behavior in response to perceived harm, such that there is the attempt at "making amends" and frequent visiting and monitoring in the nursing home setting.

Throughout the literature on developing the concept of guilt, common themes included understanding the differences between shame and guilt. Tangney et al. (1996) conducted a mixed methods study of a written narrative as well as a 31-item questionnaire and findings concluded that shame and guilt do not differ much in the contexts in which they were evaluated; however, shame was rated as more intense and involved isolation in which individuals felt more inclined to hide. In addition, early development of the conceptualization differentiated shame to be about the person themselves, whereas guilt was about the event (or action) that was done (as cited in Tanguey, 1996).

This distinguishing between guilt and shame in the literature supported my suspicions surrounding the difficulty encountered in recruitment of study participants. If,

in fact, the participants stated feelings of guilt, the shame involved in telling their story and the observation by others, there may be a desire to hide from that observation. This understanding is substantiated in the research finding that a "guilt-prone style" is far more adaptive orientation to failure and transgression than a "shame-prone" style" (as cited in Tangney, Miller, Flicker, & Barlow, 1996, p. 1267).

Guilt is identified as a contributing negative emotion found in the end-stage caregiving literature, which was primarily focused on terminal cancer patients (Funk et al., 2010). Guilt is differentiated from anxiety and depression as common indicators of psychological distress due to moral or social violations that are involved with the feeling (Glavin, Schieman, & Reid, 2011). These negative feelings along with accompanying grief and loss cannot necessarily be avoided during the transitions process; however, there is the potential that nursing therapeutics of hospice care at the very least may assist in alleviating the psychological distress and established a need to further investigate the role of guilt in bereavement.

Hospice Nurses Actions

A second major finding of this study provided evidence that hospice nurses were crucial to alleviating the suffering of family members during the transitions to residential care facilities. Their supportive role and specific actions are described in detail in Chapter 5, identifying an understanding of hospice nurses interventions with patients, families, and systems during the crisis of relocation.

Hospice care delivered in the home involves the management of the patient and the family members undergoing loss. A residential transition during the process leads to an additional crisis and a need to mitigate the shared suffering and distress due to the

disequilibrium of the transition. This disequilibrium and resultant psychological distress of guilt has the potential to contribute to complicated bereavement (Waldrop & Meeker, 2011). The supportive role and actions of the hospice nurses have been associated with a peaceful death and influence the lingering guilt in bereavement for family caregivers (Teno, Casey, & Welch, 2001).

As has been noted in a recent study of hospice experts, Ellington et al. (2014) stressed the importance of training of hospice nurses in care of the families and the critical skills needed to provide this care. Hospice and palliative care includes not only patient- but family-centered care as the "unit of care" and evidence on support for family caregiving is lacking (Hudson & Payne, 2011). Emphasis on family caregiving is a national hospice and palliative care agenda item and therefore, this current research study is critical in developing specific educational training for hospice nurses caring for the dying elderly and their families (National Hospice and Palliative Care Organization, 2014).

The results of this research and identification of an understanding of the psychological implications and stages the families undergo can assist in developing phase specific assessments and interventions. The complexities of managing transitions, navigating through systems and regulations, along with supporting the patient and family through the final stages of the dying trajectory requires increasing knowledge and skills. The training could include the following phase specific interventions:

Stage 1: Breaking Down:

Assessment tools for caregiver burden as well as motivational

interviewing techniques to help families articulate their goals for

the safety of their relatives as well as their own well-being.

Stage 2: Shattering Expectations:

Providing education for families on appropriate levels of care for their loved ones, along with supporting their decision-making process may prevent families from making additional transitions that would be burdensome.

Stage 3: Enduring the Turmoil of Transitions:

Educating families on monitoring the care as well as ongoing education on communication and conflict management between facilities and families as well as hospice.

Stage 4: Facing the Final Loss:

Providing ongoing coaching to the family about the dying process as well as information concerning treatment decisions. Providing presence to the families as much as possible with ongoing communication.

Phase 5: Justifying the Transitions:

Assessment and referral of the issues affecting bereavement.

The following recommendations were identified from the findings for the hospice nurses: 1) education and training on family and patient needs during transitions as well as the family caregiver's psychological processes, 2) identification of phase-specific interventions, 3) further research is needed in understanding guilt in bereavement for assessment and referral purposes.

Assisted Living Facilities

Initially, the focus of the study was concerning the ability for residents of ALF to age and to die in place because there is very little research conducted on EOL issues in ALF. The hospice nurses identified significant issues particular to ALF. Hospice is considered crucial to the ability to age and die in place because of the increase in staffing (hospice staff) for the resident. Even with hospice support, due to medication regulations, they may need to leave the facility. The resident of ALF has to be able to take their own medications and this may not be possible when they are dying and need to be kept comfortable. In some states, families are not permitted to give the medications without a waiver obtained from the state regulations. Residents may also need to leave if they develop a pressure ulcer from immobility at the end of their life. In addition, if a resident should develop multiple resistant staph infection, they would need to leave within an hour of diagnosis. End-of-life care or dying in place is an underdeveloped research area in ALF.

Findings from this research confirmed the literature that was reviewed. As resident's needs for nursing care increased, these needs were not met by the ALF, and residents were transferred to another institution at the end of life. When they were transitioned, it was generally to a skilled nursing facility or nursing home, which was the institution they were trying to avoid with a move to an ALF. It appears that older adults and their families may be "sold a bill of goods." This is a highly profitable industry; however, it does not appear to meet the complex needs of the population as they age and who are medically, cognitively, and functionally diverse (Padrazik, 2005).

The National Center for Health Statistics (2010) concluded the three most common ailments of residents in these communities were: high blood pressure, Alzheimer disease, and heart disease with approximately 42% suffering from some type of dementia. In this environment, the residents are provided some basic health monitoring, medication assistance, incontinence care, special diets, along with physical and occupational therapy. When compared with nursing homes, there are three primary differences: the environment, the licensed staffing, and the payer system. ALFs are mostly private pay, whereas NHs have Medicare/Medicaid benefits. However, the staffing requirements are vastly different and vary from state to state and facility to facility. Licensed staffs are not required to be present 24 hours in ALF, whereas in nursing homes, licensed nurses and certified assistance are mandated by the federal government. Assisted livings are regulated by the state government alone. ALFs have been under-researched thus far, whereas, research in SNF/NHs has made an impact on the quality of care of vulnerable adults in these facilities.

This qualitative grounded theory study developed an understanding of care transitions for these residents and families that were similar to experiences from home to ALF or home to SNF; however, the ALF environment is considered more "home-like." It is crucial to build this body of knowledge qualitatively to understand the complex and challenging issues of growing older in America and the impact of care environments on this vulnerable population.

Recommendations for Further Research

Future research is needed to determine (1) how best to manage guilt arising from care transfers for the elderly; (2) if guilt can be used as an indicator of family members' needs; (3) how to best define and achieve a "good death," which was shown in this study to assuage such guilt; and (4) a comparison study for those families who were not receiving hospice care. Two environments that were not included in this study were transitions to the hospital and an inpatient hospice facility. In the geographic region where this study was conducted, there is only one inpatient hospice facility and access was denied.

Also, further development and testing of this situation-specific theory in other settings and with a variety of cultures would also be valuable and has the potential for then creating and testing interventions for primarily caregivers. There are limited intervention studies including patients at the end of life and few family caregiver outcomes (McMillan, 2005). Further investigation into interventions that have potential to relieve distress and provide evidence for practice and policy are imperative.

Policy Implications

The estimated value of the unpaid labor of family caregivers (mostly women) is estimated to be $375 billion a year (Levin, Halper, Peist, & Gould, 2010). Delaying or avoiding nursing home placement is high on policymakers' agendas because 64 % of nursing home expenditures are covered by Medicaid. With increasing longevity and the care burdens (physical, emotional, and economic) that will surely effect families, policies that could alleviate caregiver stress, including the impact of the psychological distress of guilt of care transitions, could be implemented. These policies were identified by the

American Association for Retired Persons (AARP) Public Policy Institute (2008) and

include:

1) Expanding funding for the National Family Caregiver Support Program

2) Providing adequate funding for the Lifespan Respite Care Act

3) Providing a tax credit for caregiving to offset some of the direct expenses of

    eligible caregivers

Older adults and their family caregivers support policies that rebalance long-term care

away from institutions and toward home (Levine et al., 2010). The Institute of Medicine

(IOM) (2008) reported, "public policy has traditionally viewed informal caregivers'

service as a personal, moral obligation, and not as an extension of the workforce."

However, this does not take into consideration the economic pressures and geographic

distances that limits some families capacity to provide total care until the end of life

(Hirschfeld & Wikler, 2004). Some older adults have the finances to afford a private pay

Assisted Living Facility; however, there is a large percentage of the population that

cannot afford this luxury (Johnson & Weiner, 2006). Additionally, the majority of

residents of ALF are discharged to a SNF/NH. Navigating the complexities of declining

elderly and the burden of caregiving should be brought to the minds of all policy makers

in light of the huge influx of patients and their families that will flood the system with

needs in the coming years.

Summary

Research on the impact on family caregivers of the process of transitions of an

elderly dying loved one is limited, specifically for those enrolled in hospice. This current

study highlights the importance of hospice for elderly patients and for their families

during the complex time in transitioning the dying elderly. By increasing our knowledge of families' needs, this study can serve as a foundation of continued understanding as well as begin the translation into practice for hospice providers to assist families and patients to anticipate their physical and emotional needs. Moreover, with an ever-increasing number of families who will face intolerable burdens, policy makers need to listen to the voices of families and consider the justice of present practices.

APPENDIX A

LITERATURE REVIEW FOR THIS STUDY

Subject	Author(s)	Study Design	Sample Size & Type	Study Purpose	Results
Family Perceptions of Care	Andershed, B., 2006	Systematic search of the literature was performed in the CINAHL and Medline databases	94 papers analyzed, 59 qualitative and 35 quantitative studies with differing designs. The studies were carried out in 11 countries and were published in 34 different journals.	To review systematically research conducted during the past five years focusing on the relatives' situation and needs in EOL care.	The results were categorized in two main themes with several subthemes: (1) being a close relative – the situation: (i) exposed position – new responsibility, (ii) balance between burden and capacity, and (iii) positive values; (2) being a close relative – needs: (i) good patient care, (ii) being present, (iii) knowing and communicating, and (iv) support from and trusting relationship with the professional. The relative's feelings of security and trust in the professional were found to be of great importance.

Subject	Author(s)	Study Design	Sample Size & Type	Study Purpose	Results
Family Perceptions of Care	Marco, C. A., Buderer, N., & Thum, D., 2005	Anonymous self-administered survey mailed to families of deceased patients from five regional institutions within the Mercy Health Partners of Northwest Ohio, a division of Catholic Health Partners	A total of 969 family members participated in the study (response rate 24.9%). female (77.8%) and Caucasian (92%). Many respondents had completed some postgraduate training (45%). Respondents included the spouse of the deceased patient (45%), child (30.5%), or parent (9.9%).	To determine the opinions of family members of deceased patients regarding EOL care.	Reasons cited for satisfaction included overall care (40.2%), staff effort (23.2%), and communication (16.4%). Reasons cited for dissatisfaction included perceived incompetence (9.7%), perceived uncaring attitude (8.4%), and perceived understaffing (3.7%). Respondents were more satisfied with communication from nursing staff (88%) than physicians' communication (78%). Respondents indicated higher overall satisfaction with nursing (90%) and pastoral care (87%) than with physician care (81%).

Subject	Author(s)	Study Design	Sample Size & Type	Study Purpose	Results
Family Perceptions of Care	Pierce, 1999	Interviews with family members of decedents	Coin toss random selection method of 75 decedents from 4 counties in a Southern U.S. state. n=29, 8 male, 21 female, spouses, parents, children, siblings of the decedents aged 30-80	To ascertain suggestions family members might have to improve the death experience.	Family members made three major suggestions where the negative effects of the complex hospital system might be ameliorated when caring for dying patients: facilitate improved interaction between the dying patient and the family; improve interactions between caregivers and patients/families; and create a setting or milieu more conducive to these interactions. Further, family members related an overwhelming need to be close physically to their dying loved one; to be given permission, instruction, and opportunities to touch their loved one; to receive more information from caregivers; and to have their and their loved one's personhood acknowledged and respected.

Subject	Author(s)	Study Design	Sample Size & Type	Study Purpose	Results
Family Perceptions of Care	Port C. L., Zimmerman, S., Williams, C. S., Dobbs, D., Preisser, J. S. & Williams, S. W., 2005	Telephone interviews with the family caregivers	n=353 individuals with a diagnosis of dementia living in 35 RC/AL facilities and 10 nursing homes in four states (Florida, Maryland, New Jersey, and North Carolina)	To compare the sociodemographics, self-rated health, and involvement levels of family caregivers of residents with dementia in residential care/assisted living (RC/AL) versus nursing home settings.	Nursing home caregivers rated their health poorer than RC/AL caregivers, but there were no sociodemographic differences between the two. RC/AL caregivers rated their perception of both involvement and burden higher and engaged more frequently in monitoring the resident's health, well-being, and finances than did nursing home caregivers, although the reported time spent per week on care did not differ.
Family Perceptions of Care	Gaugler J. E., & Kane, R. L., 2007	Literature review	Following the screening of abstracts, authors retrieved 180 reports for further review and selected 62 studies for inclusion.	To examine family involvement in AL, including family structures of residents, types of involvement from family members living outside the AL facility, and outcomes for these family members.	Families visit residents frequently and provide a wide range of instrumental assistance but provide only minimal personal care. Studies of family outcomes indicated relatively high satisfaction but potential care burden as well.

Subject	Author(s)	Study Design	Sample Size & Type	Study Purpose	Results
Family Perceptions of Care	Teno, J. M., Casey, V., Welch, L. C., & Edgman-Levitan, S., 2001	Data were collected through a retrospective telephone survey with a family member who was interviewed between 3 and 6 months after the death of the patient.	One hundred fifty-six family members from an outpatient hospice service, a consortium of nursing homes, and a hospital in New England.	To examine the reliability and validity of the Toolkit After-Death Bereaved Family Member Interview to measure quality of care at the EOL from the unique perspective of family members.	Family members of persons who died with hospice service reported fewer problems in each of the six domains of medical care, gave a higher rating of the quality of care, and reported higher self-efficacy in caring for their loved ones. These results indicate that 7 of the 8 proposed problem scores or scales demonstrated psychometric properties that warrant further testing. The domain of closure demonstrated a poor correlation with overall satisfaction and requires further work. This survey could provide information to help guide quality improvement efforts to enhance the care of the dying.

Subject	Author(s)	Study Design	Sample Size & Type	Study Purpose	Results
Family Perceptions of Care	Teno, J., Clarridge, B., Casey, V., Welch, L., Wetle, T., Shield, R., & Mor, V., 2004	Mortality follow-back survey of family members or other knowledgeable informants. Via telephone interview.	1578 decedents, with a two-stage probability sample used to estimate EOL care outcomes for 1.97 million deaths from chronic illness in the United States in 2000	To evaluate the U.S. dying experience at home and in institutional settings.	For 1059 of 1578 decedents (67.1%), the last place of care was an institution. Of 519 (32.9%) patients dying at home represented by this sample, 198 (38.2%) did not receive nursing services, 65 (12.5%) had home nursing services, and 256 (49.3%) had home hospice services. About one quarter of all patients with pain or dyspnea did not receive adequate treatment, and one quarter reported concerns with physician communication. Over one third of respondents cared for by a home health agency, nursing home, or hospital reported insufficient emotional support for the patient and/or one or more concerns with family emotional support, compared with about one fifth of those receiving home hospice services. NH residents were less likely than those cared for in a hospital or home hospice services to always have been treated with respect

Subject	Author(s)	Study Design	Sample Size & Type	Study Purpose	Results
ALF & Hospice	Cartwright, J., & Kayser-Jones, J., 2003	Qualitative research which included participant observation, interviews, and document review	Four ALFs in a mixed rural-urban county in Oregon. Interviews with residents (n=4), family members (n=4), direct-care staff (n=21)	To identify the meanings that participants attributed to their and other's situations during EOL	Aging in Place not discussed. Challenges to EOL care, inadequate staffing for EOL care needs, lack of knowledge about EOL care especially knowledge deficit r/t symptom management, lack of coordination of services, limited communication between facility and hospice, differing views on roles and responsibilities for aspects of care + aspects of EOL in ALF, ALF as home, long-term, caring relationships between the resident and facility staff, emotional and physical support from staff family role hospice and family involvement may both be critical for EOL care in ALFs. Staying in AL seen as home, wanted to stay to death

Subject	Author(s)	Study Design	Sample Size & Type	Study Purpose	Results
ALF and Hospice	Cartwright, J.C., Miller, L. & Volpin, M., 2009	A qualitative descriptive design using semistructured interviews	Purposive sampling of participants from five ALFs and five hospice programs throughout Oregon. Included 18 hospice RNs, 6 ALF RNs, 9 MAs, and 5 CGs who provided personal care to residents.	To describe good quality care at the EOL for hospice-enrolled residents in assisted living facilities (ALFs)	ALF administrators need to carefully consider whether their facility can support dying in place and if so, what is needed for this to happen. The relationships between the resident and the ALF staff, and among care providers, are critical in promoting good quality EOL care. Important features of care-provider relationships included strong teamwork, good communication, use of multiple sources of knowledge in providing care, and shared expectations about managing potential problems.

Subject	Author(s)	Study Design	Sample Size & Type	Study Purpose	Results
ALF and Hospice	Munn, J. C., Hanson, L. C., Zimmerman, S., Sloane, P. D., & Mitchell, C. M., 2006	Structured, retrospective telephone interviews with family and staff	A stratified sample of 26 NH and 55 RC/AL facilities in four states. Family members (n=97) and long-term care (LTC) staff (n= 104) identified as most involved in care of 124 residents who died over a 15-month period.	To examine whether hospice enrollment for nursing home (NH) and residential care/assisted living (RC/AL) residents near the EOL is associated with symptoms and symptom management, personal care, spiritual support, and family satisfaction.	Rates of hospice use observed in this study (22%) were considerably higher than previously reported, although persons with dementia may continue to be under-referred. Hospice use is targeted to dying residents with higher levels of reported pain and dyspnea. Because difference in care largely disappears in cases when death was expected, LTC staff seem to be well positioned to provide EOL care for their residents and are advised to remain sensitive to instances in which death may be expected.

Subject	Author(s)	Study Design	Sample Size & Type	Study Purpose	Results
ALF and Hospice	Dixon, S., Fortner, J., & Travis, S. S., 2002	3 focus groups	Family n=4 Admin of AL n=6 Hospice team members n=8	Clarify EOL issues in assisted-living communities	Aging in Place not discussed. Resident characteristics not discussed. Challenges to EOL care staffing levels staff knowledge communication hospice needing to adjust to setting. Family/resident understanding of levels of care/cost. Coordination and accountability for care. Lack of local family. Late referrals + aspects of EOL in ALF sense of community care & attention from staff involvement of hospice family role not discussed. Staying in AL. All three groups support right of aging in/dying in place & role of hospice to achieve goal

Subject	Author(s)	Study Design	Sample Size & Type	Study Purpose	Results
Aging and Dying in Place	Ball M. M., Perkins, M. M., Whittington, F. J., Connell, B. R., Hollingsworth, C., King, S. V., . . . Combs, B. L., 2004	Grounded theory, use of participant observation, interviews, and review of documents	Five assisted living facilities (ALFs) in Georgia (called "personal care homes"). Purposive, maximum variation sampling greatest variation re: race and socioeconomic status of residents, size, level of resources, and geographic location Interviews with residents (n=39), family members (n=28), direct-care staff and administrators (n=39) Total of 457 visits, 1436 hrs. of observation	To gain an understanding of the process of aging in place in ALFs and the factors influencing this phenomenon in a variety of AL contexts	Aging in Place. The ability of ALF residents to age in place was dependent on the ''fit'' between the capacity of both residents and facilities to manage decline, which was, for most residents, inevitable. Two types of strategies to manage decline: those aimed at preventing further decline and those focusing on response to decline. Managing decline often = managing risk, for both resident and institution. Resident characteristics most experienced inevitable decline. Discharges r/t confused, disruptive or risky behavior 2/2 dementia or mental illness EOL care not discussed. Family role described as "support." Specific examples provided. Family as key to maintain residence. Staying in AL Most residents and families wanted the resident to be able to stay in AL as function decreased, saw AL as home

Subject	Author(s)	Study Design	Sample Size & Type	Study Purpose	Results
Aging and Dying in Place	Chapin R., & Dobbs-Kepper, D., 2001	Facilities had a choice of completing a survey by mail or telephone.	141 facilities in Kansas. Total occupancy capacity for these facilities was 5,110, and the current resident census was 3,579. The median occupancy rate was 75%. The capacity size ranged from 6 units to 227 units, with a median size of 56 units.	To examine implementation of the aging-in-place philosophy in 1 Midwestern state (Kansas).	Residents' capacity to age in place was limited by facility admission and discharge policies that were more restrictive than state regulations in the areas of behavioral problems, incontinence, and cognition. In general, assisted living facility policies in Kansas were more restrictive than admission and discharge policies found nationally.
Aging and Dying in Place	Degenholtz, H. B., Rhee, Y., & Arnold, R. M., 2004	Secondary analysis of data from a nationally representative longitudinal study.	The analytic sample was based on 539 informants for people who did not die suddenly or unexpectedly, representing 1,590,892 people older than 70 years of age who lived in the community in 1993 and died by 1995.	To test the hypothesis that people with living wills are less likely to die in a hospital than in their residence before death.	Having a living will was associated with lower probability of dying in a hospital for nursing home residents and people living in the community. For people living in the community, the probability of in-hospital death decreased from 0.65 (95% CI, 0.58 to 0.71) to 0.52 (CI, 0.42 to 0.62). For people living in nursing homes, the probability of in-hospital death decreased from 0.35 (CI, 0.23 to 0.49) to 0.13 (CI, 0.07 to 0.22).

Subject	Author(s)	Study Design	Sample Size & Type	Study Purpose	Results
Aging and Dying in Place	Hawes, C., Phillips, C. D., Rose, M., Holan, S. & Sherman, M., 2003	1998–1999 telephone survey of ALFs selected via multistage probability sampling; residents randomly selected within each high service–high privacy ALF (41% of eligible settings) and interviewed in person (n=184, 558).	National via 60 geographic areas; sampling units. 12.1% married 70.8% widowed 7.2% divorced 9.9% never married		Significant differences exists between policies and performance in various ALFS
Aging and Dying in Place	Bern-Klug, M., 2009	Secondary analysis of qualitative ethnographic data. Field notes, medical chart data, and transcribed interviews.	45 residents in two nursing homes in a large Midwestern city	The purpose of this study is to develop a framework for organizing social interactions related to EOL care and to characterize the social construction of dying in two nursing homes.	A new framework of five categories to name the stance toward the possibility of dying is presented and illustrated with cases. The categories include: dying allowed, dying contested, mixed message dying, not dying, and not enough information. Over half the resident cases were classified as mixed message dying or not enough information, which speaks to the ambiguity regarding care plan goals found in the two nursing homes in the study.

Subject	Author(s)	Study Design	Sample Size & Type	Study Purpose	Results
Aging and Dying in Place	Zimmerman, S., Sloane P., Hanson L., Mitchell C., & Shy, A., 2003	Part of a larger cohort study. Staff were interviewed retrospectively regarding care provided during residents' last month of life.	Ninety-nine staff provided their perceptions of EOL care for 99 decedents from 74 residential care/assisted living facilities and nursing homes in four states	To understand staff perceptions of EOL care, perceived need for improvement of care and differences by type setting.	Both residential care/assisted living and nursing home staff reported a need for more staff education and nursing assistant time, as well as more use of volunteers. The two lowest ranked items for both facility types were involvement of hospice and encouragement for staff to attend funeral services. Nursing home staff perceived a greater need for improvement than residential care/assisted living staff in all 11 areas.
Transitions	Mezey, M., Dubler, N. N., Mitty, E., & Brody, A. A., 2002	Literature review	Not given	To identify major research needs related to quality of life at the EOL and quality of the dying process for vulnerable older people at home, in assisted living facilities, in skilled nursing facilities, and in prisons.	The science is generally weak in relationship to what is known about quality of life at the EOL and quality of dying for vulnerable older adults in different settings. Participant decisional capacity is a barrier to conducting research in these settings.

Subject	Author(s)	Study Design	Sample Size & Type	Study Purpose	Results
Transitions	Teno, J. M., Clarridge, B. R., Casey, V., Welch, L. C., Wetle, T., Shield, R., & Mor, V., 2004	Mortality follow-back survey of family members or other knowledgeable informants representing decedents who passed in 2000. Telephone interviews about the patient's experience at the last place of care at which the patient spent more than 48 hours.	A two-stage probability sample 9-10 (designed to select states, then individuals within states) was used to generate national estimates of the dying experience. A total of 1578 interviews from 8 U.S. states that represented 1.97 million deaths in the year 2000	To evaluate the US dying experience at home and in institutional settings.	This research indicates that high-quality EOL care results when health care professionals (1) ensure desired physical comfort and emotional support, (2) promote shared decision-making, (3) treat the dying person with respect, (4) provide information and emotional support to family members, and (5) coordinate care across settings.

Subject	Author(s)	Study Design	Sample Size & Type	Study Purpose	Results
Transitions	Gozalo, P., Teno, J. M., Mitchell, S. L., Skinner, J., Bynum, J., Tyler, D., & Mor, V., 2011	Quantitative study linked nationwide data from the Medicare Minimum Data Set and claims files from 2000 through 2007	474,829 nursing home decedents	To examine health care transitions among Medicare decedents with advanced cognitive and functional impairment who were nursing home residents 120 days before death	Among 474,829 nursing home decedents, 19.0% had at least one burdensome transition (range, 2.1% in Alaska to 37.5% in Louisiana). In adjusted analyses, Blacks, Hispanics, and those without an advance directive were at increased risk. Nursing home residents in regions in the highest quintile of burdensome transitions (as compared with those in the lowest quintile) were significantly more likely to have a feeding tube (adjusted risk ratio, 3.38), have spent time in an ICU in the last month of life (adjusted risk ratio, 2.10), have a stage IV decubitus ulcer (adjusted risk ratio, 2.28), or have had a late enrollment in hospice (adjusted risk ratio, 1.17).

Subject	Author(s)	Study Design	Sample Size & Type	Study Purpose	Results
Transitions	Coleman et al., 2004	Quasi-experimental design whereby subjects receiving the intervention were compared with control subjects derived from administrative data	Intervention patients (n=158) were recruited directly from the contract hospital. Control patients (n=1,235) inclusion criteria included patients aged 65 and older hospitalized between July 1, 2001, and September 1, 2002	To test whether an intervention designed to encourage older patients and their caregivers to assert a more active role during care transitions can reduce hospitalization rates.	The adjusted odds ratio comparing rehospitalization of intervention subjects with that of controls was 0.52 (95% confidence interval (CI)50.28–0.96) at 30 days, 0.43 (95% CI50.25–0.72) at 90 days, and 0.57 (95% CI50.36–0.92) at 180 days. Intervention patients reported high levels of confidence in obtaining essential information for managing their condition, communicating with members of the health care team, and understanding their medication regimen.
Transitions	Davies, S., 2005	A constructivist study; relatives' experiences were re-analyzed in relation to the extent to which they reflected the domains of the theory of nursing transitions	Original study - 37 qualitative interviews involving 48 close family members of older people who had recently moved to a nursing home, from three nursing homes.	To explore the extent to which Meleis's middle-range theory of nursing transitions is supported by the findings of a study exploring relatives' experiences of the move to a nursing home.	All domains of the theory of nursing transition were supported by the data generated within the study. However, the model failed to represent adequately the interactive and dynamic nature of relationships between formal and informal caregivers in the nursing home context.

Subject	Author(s)	Study Design	Sample Size & Type	Study Purpose	Results
Transitions	Aaltonen, M., Rissanen, P., Forma, L., Raitanen, J., & Jylha, M., 2012	Data were derived from Finnish national registers; negative binomial regression analyses were used to analyze the impact of dementia on number of transitions among people with and without dementia and to adjust the number for age, gender, and other diagnoses	All those who died in 2002 and 2003 at the age of 70 or older (n=70,366) in Finland	To compare the number and timing of transitions between care settings in the last 2 years of life among older people with and without dementia.	The group that lived at home 2 years before death people with a dementia diagnosis had 32% more care transitions than people without dementia, while the group that was in residential care facility 2 years before death people with dementia had 12% fewer moves than those without dementia The average number of transition was highest in last 3 months of life. People with dementia had their last move more often between care facilities and hospitals offering basic health care than people without dementia.

Subject	Author(s)	Study Design	Sample Size & Type	Study Purpose	Results
Transitions	Boockvar et al., 2004	Prospective cohort study. Patient or surrogate interview, research nurse assessment, and medical record review.	A total of 562 patients hospitalized for hip fracture discharged alive in 1997 to 1998.	To describe the incidence and patterns of patient relocation after hip fracture, identify factors associated with relocation, and examine effect of relocation on outcomes.	During 6 months of follow-up, the mean number of relocations per patient standard deviation was 3.5 1.5 (range 2–10). Forty-one % of relocations were between home and hospital, 36% between rehabilitation or nursing facility and hospital, 17% between rehabilitation or nursing facility and home, and 4% between two rehabilitation/nursing facilities. In a Poisson regression model that controlled for patient characteristics, hospital course, and length of follow-up, factors associated with relocation (Po.05) were absence of dementia, in-hospital delirium, one or more new impairments at hospital discharge, hospital discharge other than to and not living at home alone prefracture. Relocation was not gnificantly associated with immobility or mortality at 6 months.

APPENDIX B

RECRUITMENT STRATEGIES

Dear Faith Community Nurses:

As an introduction, I have been involved in Faith Community Nursing for a number of years. I began the program at Holy Apostles Catholic Church in 2000 and I have been an advisory board member for many years (2000-2008) and assisted with the Preparatory course as well as the annual retreat.

I am conducting a study for my dissertation at the University of Utah. My study involves residents of assisted living facilities who were enrolled in hospice care and were transitioned out of the facility at the end of their lives. I will be interviewing both families of the residents as well as hospice nurses who have cared for residents (but not these particular residents). As Faith Community Nurses, many of you have worked with families who may have had this experience. If you know of a family, I am requesting that you contact them and ask if they would be willing to be interviewed for my study. I will provide a full description of the study and as you know there will be an informed consent document as well as Institutional Review Board approval to conduct the study.

Please contact me if you have any questions and also to provide me with the contact information of the families. I can be reached at 208-870-1253 or kimmartz@boisestate.edu. Thank you for assisting me with this study.

Kim Martz, MSN, RN

Church Bulletin Advertisement:

If you have had a loved one in an assisted living facility receiving hospice care who needed to transfer out of the facility at the end of their lives, I would like to interview you or your family members. This research study will serve as my dissertation at the University of Utah. Please contact me if you would like to participate, or for further details at 208-870-1253 or kimmartz@boisestate.edu.

APPENDIX C

INFORMED CONSENT DOCUMENTS, DEMOGRAPHIC DATA SHEETS

Consent Document
for Minimal Risk Research

Bereaved Family Member Consent

BACKGROUND

You are being asked to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you want to volunteer to take part in this study.

The purpose of the study is to explore the perception and impact on families and hospice nurses when a dying person is transferred from assisted living facilities to other care facilities. This study will identify and order the impact of transitions by interviewing family members and hospice nurses that were involved in the transition of a relative from an assisted living at the end of life.

STUDY PROCEDURE

It will take you approximately 2 hours to complete this study. As part of this study you will be asked to take part in a face-to-face interview. However, if it is inconvenient, we may talk by a phone or skype. You will be asked to tell me about your experience when your relative was transferred out of the assisted living at the end of life. You may be contacted at the end of the study for further information and invited to participate in a small focus group at that time.

RISKS

The risks of this study are minimal. You may feel upset thinking about or talking about personal information related to death of a loved one. These risks are similar to those you experience when discussing personal information with others. If you feel upset from this experience, you can tell the researcher, and he/she will tell you about resources available to help.

BENEFITS

There are no direct benefits for taking part in this study. However, we hope the information we get from this study may help develop a greater understanding of the impact of transitions for families and residents of assisted living and may influence regulations and policies in the future.

CONFIDENTIALITY

We will keep all research records that identify you private to the extent allowed by law. Records about you will be kept in locked filing cabinets, and on computers protected with passwords or encryption. Only those who work with this study or are performing their job duties for the University will be allowed access to your information. Your name will be kept with your responses from interviews in the locked locations described above, however, in publications; your name will be removed.

You will be anonymous except in cases where the researcher is legally obligated to report specific incidents. However, if you disclose actual or suspected abuse, neglect, or exploitation of a child, or disabled or elderly adult, the researcher or any member of the study staff must, and will, report this to Child Protective Services (CPS), Adult Protective Services (APS) or the nearest law enforcement agency.

I am requesting your permission to retain your interviews, both the recording and the transcript, beyond the end of this study, to use in subsequent research projects. Your name will not be associated with the interviews, and they will be secured in locked cabinets or password encrypted computers.

PERSON TO CONTACT

If you have questions, complaints or concerns about this study, you can contact Dr. Janice Morse at 801-585-3930 from 9 a.m. to 5 p.m. on weekdays. If you feel you have been harmed as a result of participation, please call Dr. Morse at 801-953-0285 after hours and on weekends or you may email her at Janice.Morse@nurs.utah.edu

Institutional Review Board: Contact the Institutional Review Board (IRB) if you have questions regarding your rights as a research participant. Also, contact the IRB if you have questions, complaints or concerns which you do not feel you can discuss with the investigator. The University of Utah IRB may be reached by phone at (801) 581-3655 or by e-mail at irb@hsc.utah.edu.

Research Participant Advocate: You may also contact the Research Participant Advocate (RPA) by phone at (801) 581-3803 or by email at participant.advocate@hsc.utah.edu.

VOLUNTARY PARTICIPATION

It is up to you to decide whether to take part in this study. Refusal to participate or the decision to withdraw from this research will involve no penalty or loss of benefits to which you are otherwise entitled. This will not affect your relationship with the investigator.

COSTS AND COMPENSATION TO PARTICIPANTS
There are no costs or compensation related to participation in this study.

CONSENT:
I confirm that I have read this consent and authorization document and have had the opportunity to ask questions. I will be given a signed copy of the consent and authorization form to keep.

I agree to participate in this research study and authorize you to use and disclose health information about me for this study, as you have explained in this document.

_____
Participant's Name

_____   _____
Participant's Signature   Date

_____
Name of Person Obtaining Consent

_____   _____
Signature of Person Obtaining Consent   Date

Consent Document
for Minimal Risk Research

Hospice Nurse Consent

BACKGROUND

You are being asked to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you want to volunteer to take part in this study.

The purpose of the study is to explore the perception and impact on families and hospice nurses when a dying person is transferred from assisted living facilities to other care facilities. This study will identify and order the impact of transitions by interviewing family members and hospice nurses that were involved in the transition of a relative from an assisted living at the end of life.

STUDY PROCEDURE

It will take you approximately 2 hours to complete this study. As part of this study you will be asked to take part in a face-to-face interview. However, if it is inconvenient, we may talk by a phone or Skype. You will be asked to tell me about your experience when your patient was transferred out of the assisted living at the end of life. You may be contacted at the end of the study for further information and invited to participate in a small focus group at that time.

RISKS

The risks of this study are minimal. You may feel upset thinking about or talking about personal information related to death of your patient. These risks are similar to those you experience when discussing personal information with others. If you feel upset from this experience, you can tell the researcher, and he/she will tell you about resources available to help.

There will be no effect on your employment with a Hospice Agency due to your participation nor refusal to participate in this study. You will be anonymous.

BENEFITS

There are no direct benefits for taking part in this study. However, we hope the information we get from this study may help develop a greater understanding of the impact of transitions for families and residents of assisted living and may influence regulations and policies in the future.

CONFIDENTIALITY

We will keep all research records that identify you private to the extent allowed by law. Records about you will be kept in locked filing cabinets, and on computers protected with passwords or encryption. Only those who work with this study or are performing their job duties for the University will be allowed access to your information. Your name will be kept with your responses from interviews in the locked locations described above, however, in publications; your name will be removed.

You will be anonymous except in cases where the researcher is legally obligated to report specific incidents. However, if you disclose actual or suspected abuse, neglect, or exploitation of a child, or disabled or elderly adult, the researcher or any member of the study staff must, and will, report this to Child Protective Services (CPS), Adult Protective Services (APS) or the nearest law enforcement agency.

I am requesting your permission to retain your interviews, both the recording and the transcript, beyond the end of this study, to use in subsequent research projects. Your name will not be associated with the interviews, and they will be secured in locked cabinets or password encrypted computers.

PERSON TO CONTACT

If you have questions, complaints or concerns about this study, you can contact Dr. Janice Morse at 801-585-3930 from 9 a.m. to 5 p.m. on weekdays. If you feel you have been harmed as a result of participation, please call Dr. Morse at 801-953-0285 after hours and on weekends or you may email her at Janice.Morse@nurs.utah.edu

Institutional Review Board: Contact the Institutional Review Board (IRB) if you have questions regarding your rights as a research participant. Also, contact the IRB if you have questions, complaints or concerns which you do not feel you can discuss with the investigator. The University of Utah IRB may be reached by phone at (801) 581-3655 or by e-mail at irb@hsc.utah.edu.

Research Participant Advocate: You may also contact the Research Participant Advocate (RPA) by phone at (801) 581-3803 or by email at participant.advocate@hsc.utah.edu.

VOLUNTARY PARTICIPATION

It is up to you to decide whether to take part in this study. Refusal to participate or the decision to withdraw from this research will involve no penalty or loss of benefits to

which you are otherwise entitled. This will not affect your relationship with the investigator.

COSTS AND COMPENSATION TO PARTICIPANTS
There are no costs or compensation related to participation in this study.

CONSENT:
I confirm that I have read this consent and authorization document and have had the opportunity to ask questions. I will be given a signed copy of the consent and authorization form to keep.

I agree to participate in this research study and authorize you to use and disclose health information about me for this study, as you have explained in this document.

_____
Participant's Name

_____   _____
Participant's Signature   Date

_____
Name of Person Obtaining Consent

_____   _____
Signature of Person Obtaining Consent   Date

Participant Demographic Data

Bereaved Family Member

Age: _____

Gender: F   M

Date of death of Loved one: _____

Did they have advanced directives prior to enrolling in hospice? _____

Relationship to deceased ALF resident: _____

Location of Transfer from the ALF facility: _____

Length of time spent in new location: _____

Total Length of Stay in ALF : _____

Hospice LOS: _____

Participant Demographic Data

Hospice Nurse

Age: _____

Gender: F   M

How long have you been a Hospice Nurse? _____

Level of education: _____

Location of Transfer from the ALF facility for your patient: _____

Length of time spent in new location: _____

Hospice LOS: _____

APPENDIX D

LETTERS OF SUPPORT

BOISE STATE UNIVERSITY

College of Health Sciences

Office of the Dean

1910 University Drive   Boise, Idaho 83725-1800

phone 208-426-1678
fax 208-426-3469
http://hs.boisestate.edu

December, 4, 2012

Kim Martz, MSN, RN
Assistant Professor
Boise State University
1910 University DR.
Boise, ID 83725

Re: University of Utah IRB and Letter of support

Dear Kim,

I am pleased to learn that you are in the dissertation phase of your doctoral studies and making application to the University of Utah Institutional Review Board. Per our conversation concerning recruitment of faculty and staff from the College of Health Science at Boise State University, pending the University of Utah IRB approval, I fully support your access to the email address and recruitment for our faculty, staff and adjunct faculty.
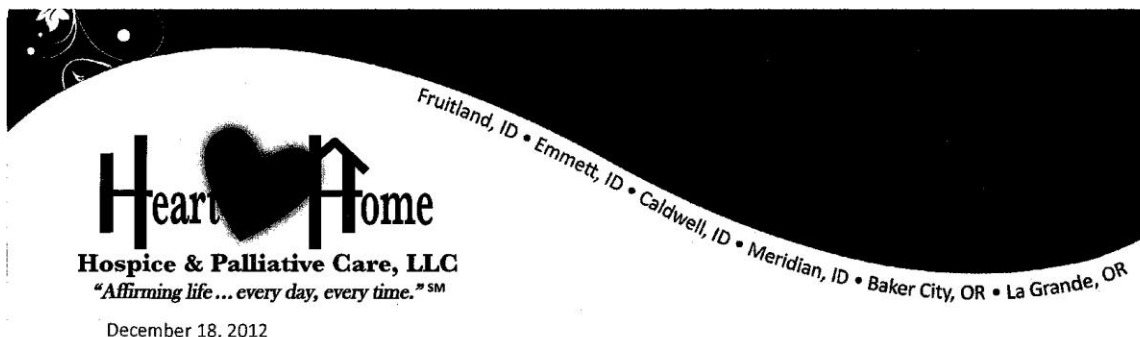
Thank you for providing a copy of the recruitment procedures and a draft of the email that will be sent out to our faculty and staff. We support your research and this recruitment and look forward to learning the results of your study.

Sincerely,

Tim Dunnagan,
Dean, College of Health Science, Boise State University

Hear♥ ome
Hospice & Palliative Care, LLC
"Affirming life ... every day, every time." SM

Fruitland, ID • Emmett, ID • Caldwell, ID • Meridian, ID • Baker City, OR • La Grande, OR

December 18, 2012

Kim Martz, MSN, RN
Assistant Professor
Boise State University
1910 University Dr
Boise, ID 83725

Dear Kim:

We at Heart 'n Home Hospice & Palliative Care are pleased to learn about your plans conduct research for your dissertation. Your proposal, "Bereaved Family Member and Hospice Nurses Perspectives of Resident's Transitions from Assisted Living Facilities at the End of Life Care" will provide an in-depth understanding of the challenges facing families in this relatively new environment of study. I understand your proposal will generate a theory describing the implications. These implications will be helpful to explain to policy-makers the issues involved in end of life care for older adults in assisted living facilities.

Your study is aligned with our desire to help individuals die in place and the impact that it has on families' financial burden and stress could influence state regulations and perhaps even national regulations. Your study aligns with the National Hospice and Palliative Care Organizations Quality Measures in addition to helping our organization better educate and inform families at these most difficult times.

Please be assured that our agency will be available to support your plans. Our database will enable you to locate a portion of the sample for your study. In addition, we are willing to contact families and explain the study and its importance to future patients and their families.

Thank you for contacting us about your proposal. I enthusiastically support this effort and will help to facilitate its implementation in any way that I can.

Sincerely,

Cindy Lee, RN, CHPN, CHPCA

Cindy Lee, RN, CHPN, CHPCA
CEO/Administrator
Heart 'n Home Hospice & Palliative Care, LLC
1100 NW 12th Street
Fruitland, ID 83619

1100 NW 12th Street • Fruitland, ID 83619 • PH: 208-452-2663 • FX: 208-452-2665

1-800-HOSPICE (800-467-7423) • www.goHOSPICE.com

HORIZON
HOME HEALTH & HOSPICE

May 21, 2012

Kim Martz, MSN, RN
Assistant Professor
Boise State University
1910 University Drive
Boise, ID 83725

Dear Kim:

We at Horizon Home Health and Hospice are pleased to learn about your plans conduct research for your dissertation. Your proposal, "Bereaved Family Member and Hospice Nurses Perspectives of Resident's Transitions from Assisted Living Facilities at the End of Life Care" will provide an in-depth understanding of the challenges facing families in this relatively new environment of study. I understand your proposal will generate a theory describing the implications. These implications will be helpful to explain to policy-makers the issues involved in end of life care for older adults in assisted living facilities.

Your study is aligned with our desire to help individuals die in place and the impact that it has on families' financial burden and stress could influence state regulations and perhaps even national regulations. Your study aligns with the National Hospice and Palliative Care Organizations Quality Measures in addition to helping our organization better educate and inform families at these most difficult times.

Please be assured that our agency will be available to support your plans. Our database will enable you to locate a portion of the sample for your study. In addition, we are willing to contact families and explain the study and its importance to future patients and their families.

Thank you for contacting us about your proposal. I enthusiastically support this effort and will help to facilitate its implementation in any way that I can.

Sincerely,

Amanda Corn RN

Amanda Corn, RN, CHPN
Hospice – Clinical Director
Horizon Home Health and Hospice

208-871-0362

Delivering Life Changing Service

Boise/Meridian	Boise/Meridian Hospice	Burley	Caldwell/Nampa
(208) 888-7877	(208) 884-5051	(208) 678-8500	(208) 455-1990
(208) 888-7987 Fax	(208) 884-5054 Fax	(208) 678-8600 Fax	(208) 455-4274 Fax
Emmett	Mountain Home	Twin Falls	Weiser
(208) 365-1693	(208) 587-6854	(208) 733-2840	(208) 549-2104
(208) 365-1694 Fax	(208) 587-6872 Fax	(208) 733-2835 Fax	(208) 549-2108 Fax

APPENDIX E

CONSENT COVER LETTERS

Consent Cover Letter
Assisted Living Facility Administrators or Staff
Bereaved Family Member and Hospice Nurses Perspectives of
Transitions to and between Residential Care Facilities

The purpose of the study is to explore the perception and impact on families and hospice nurses when a dying person is transferred from home to an assisted living facility and from assisted living to skilled nursing/nursing home residential care facilities. This study will identify and order the impact of transitions by interviewing family members and hospice nurses as well as assisted living facility administrators and staff that were involved in the transition of a relative from an assisted living at the end of life.

It may take you approximately 2 hours to complete this study. As part of this study you will be asked to take part in a face-to-face interview. However, if it is inconvenient, we may talk by a phone or Skype. You will be asked to tell me about experiences when your residents were transferred out of the assisted living at the end of life. You may be contacted at the end of the study for further information and invited to participate in a small focus group at that time.

The interview will be digitally recorded and will not include the name of the participant. Each interview will be given a code and the code will be kept with the PI in a password protected file. You will be anonymous except in cases where the researcher is legally obligated to report specific incident related to abuse, neglect or exploitation of an elderly adult.

Your interview transcript will be retained for use in subsequent research projects. Your name will not be associated with the interviews and the data will be secured in locked cabinets and or password encrypted computers.

If you have any questions, complaints or if you feel you have been harmed by this research please contact Dr. Janice Morse at 801-585-3930 from 9 a.m. to 5 p.m. on weekdays. If you feel you have been harmed as a result of participation, please call Dr. Morse at 801-953-0285 after hours and on weekends or you may email her at Janice.Morse@nurs.utah.edu

Contact the Institutional Review Board (IRB) if you have questions regarding your rights as a research participant. Also, contact the IRB if you have questions, complaints or concerns which you do not feel you can discuss with the investigator. The University of Utah IRB may be reached by phone at (801) 581-3655 or by e-mail at irb@hsc.utah.edu.

Participation in this study is voluntary. You can choose not to take part. You can choose not to finish the interview at any time. The interview will serve as your consent to participate. Thank you for your participation.

«Institution»
«IRB»
«Image:Stamp»   «Approved» «ApprovedDate»
«Expiration» «ExpirationDate»
«Number»

Consent Cover Letter
Bereaved Family Members
Bereaved Family Member and Hospice Nurses Perspectives of Transitions to and between Residential Care Facilities

The purpose of the study is to explore the perception and impact on families and hospice nurses when a dying person is transferred from home to an assisted living facility and from assisted living to skilled nursing/nursing home residential care facilities. This study will identify and order the impact of transitions by interviewing family members and hospice nurses that were involved in the transition of a relative at the end of life.

It may take you approximately 2 hours to complete this study. As part of this study you will be asked to take part in a face-to-face interview. However, if it is inconvenient, we may talk by a phone or Skype. You will be asked to tell me about your experience when your relative was transferred the end of life. You may be contacted at the end of the study for further information. A $25.00 gift certificate will be provided as compensation for your time.

The interview will be digitally recorded and will not include the name of the participant. Each interview will be given a code and the code will be kept with the PI in a password protected file. You will be anonymous except in cases where the researcher is legally obligated to report specific incident related to abuse, neglect or exploitation of an elderly adult.

Your interview transcript will be retained for use in subsequent research projects. Your name will not be associated with the interviews and the data will be secured in locked cabinets and or password encrypted computers.

If you have any questions, complaints or if you feel you have been harmed by this research please contact Dr. Janice Morse at 801-585-3930 from 9 a.m. to 5 p.m. on weekdays. If you feel you have been harmed as a result of participation, please call Dr. Morse at 801-953-0285 after hours and on weekends or you may email her at Janice.Morse@nurs.utah.edu

Contact the Institutional Review Board (IRB) if you have questions regarding your rights as a research participant. Also, contact the IRB if you have questions, complaints or concerns which you do not feel you can discuss with the investigator. The University of Utah IRB may be reached by phone at (801) 581-3655 or by e-mail at irb@hsc.utah.edu.

Participation in this study is voluntary. You can choose not to take part. You can choose not to finish the interview at any time. The interview will serve as your consent to participate. Thank you for your participation.

«Image:Stamp»	«Institution»
	«IRB»
	«Approved» «ApprovedDate»
	«Expiration» «ExpirationDate»
	«Number»

Consent Cover Letter
Skilled Nursing Home Administrators or Staff
Bereaved Family Member and Hospice Nurses Perspectives of
Transitions to and between Residential Care Facilities

The purpose of the study is to explore the perception and impact on families and hospice nurses when a dying person is transferred from home to an assisted living facility and from assisted living to skilled nursing/nursing home residential care facilities. This study will identify and order the impact of transitions by interviewing family members and hospice nurses as well as assisted living facility administrators and staff that were involved in the transition of a relative from an assisted living at the end of life.

It may take you approximately 2 hours to complete this study. As part of this study you will be asked to take part in a face-to-face interview. However, if it is inconvenient, we may talk by a phone or Skype. You will be asked to tell me about experiences when your residents were transferred out of the assisted living at the end of life. You may be contacted at the end of the study for further information and invited to participate in a small focus group at that time.

The interview will be digitally recorded and will not include the name of the participant. Each interview will be given a code and the code will be kept with the PI in a password protected file. You will be anonymous except in cases where the researcher is legally obligated to report specific incident related to abuse, neglect or exploitation of an elderly adult.

Your interview transcript will be retained for use in subsequent research projects. Your name will not be associated with the interviews and the data will be secured in locked cabinets and or password encrypted computers.

If you have any questions, complaints or if you feel you have been harmed by this research please contact Dr. Janice Morse at 801-585-3930 from 9 a.m. to 5 p.m. on weekdays. If you feel you have been harmed as a result of participation, please call Dr. Morse at 801-953-0285 after hours and on weekends or you may email her at Janice.Morse@nurs.utah.edu

Contact the Institutional Review Board (IRB) if you have questions regarding your rights as a research participant. Also, contact the IRB if you have questions, complaints or concerns which you do not feel you can discuss with the investigator. The University of Utah IRB may be reached by phone at (801) 581-3655 or by e-mail at irb@hsc.utah.edu.

Participation in this study is voluntary. You can choose not to take part. You can choose not to finish the interview at any time. The interview will serve as your consent to participate. Thank you for your participation.

«Institution»
«IRB»
«Image:Stamp»   «Approved» «ApprovedDate»
«Expiration» «ExpirationDate»
«Number»

Consent Cover Letter
Hospice Nurses
Bereaved Family Member and Hospice Nurses Perspectives of
Transitions to and between Residential Care Facilities

The purpose of the study is to explore the perception and impact on families and hospice nurses when a dying person is transferred from home to an assisted living facility or to a skilled nursing/nursing home residential care facility. This study will identify and order the impact of transitions by interviewing family members and hospice nurses that were involved in the transition of a relative at the end of life.

It may take you approximately 2 hours to complete this study. As part of this study you will be asked to take part in a face-to-face interview. However, if it is inconvenient, we may talk by a phone or Skype. You will be asked to tell me about your experience when your patient was transferred at the end of life. You may be contacted at the end of the study for further information and invited to participate in a small focus group at that time.

The interview will be digitally recorded and will not include the name of the participant. Each interview will be given a code and the code will be kept with the PI in a password protected file. You will be anonymous except in cases where the researcher is legally obligated to report specific incident related to abuse, neglect or exploitation of an elderly adult.

Your interview transcript will be retained for use in subsequent research projects. Your name will not be associated with the interviews and the data will be secured in locked cabinets and or password encrypted computers.

If you have any questions complaints or if you feel you have been harmed by this research please contact Dr. Janice Morse at 801-585-3930 from 9 a.m. to 5 p.m. on weekdays. If you feel you have been harmed as a result of participation, please call Dr. Morse at 801-953-0285 after hours and on weekends or you may email her at Janice.Morse@nurs.utah.edu

Contact the Institutional Review Board (IRB) if you have questions regarding your rights as a research participant. Also, contact the IRB if you have questions, complaints or concerns which you do not feel you can discuss with the investigator. The University of Utah IRB may be reached by phone at (801) 581-3655 or by e-mail at irb@hsc.utah.edu.

Participation in this study is voluntary. You can choose not to take part. You can choose not to finish the interview at any time. The interview will serve as your consent to participate. Thank you for your participation.

«Image:Stamp»	«Institution»
	«IRB»
	«Approved» «ApprovedDate»
	«Expiration» «ExpirationDate»
	«Number»

REFERENCES

Aaltonen, M., Rissanen, P., Forma, L., Raitanen, J., & Jylhä, M. (2012). The impact of dementia on care transitions during the last two years of life. *Age and Ageing, 41*(1), 52-57. doi: 10.1093/ageing/afr133.

Abarshi, E. (2010). Transitions between care settings at the end of life in The Netherlands: Results from a nationwide study. *Palliative Medicine, 24*(2*)*, 166-74.

Administration on Aging. (2008). Administration for Community Living. Retrieved: http://www.acl.gov/Get_Help/Help_Caregivers/Index.aspx.

Akiyama, A., Numata, K., & Mikami, H. (2010). Importance of end-of-life support to minimize caregiver's regret during bereavement for the elderly for better subsequent adaptation to bereavement. *Archives of Gerontology and Geriatrics, 50*, 175-178.

American Association for Retired Persons (AARP) (2014). In brief: Valuing the invaluable: A new look at the economic value of family caregiving. *Public Policy Institute*, INB, *142*. Retrieved on June 12, 2014: http://assets.aarp.org/rgcenter/il/inb142_caregiving.pdf.

Andershed, B. (2006). Relatives in end-of-life care - Part 1: A systematic review of the literature the five last years, January 1999-February 2004. *Journal of Clinical Nursing, 15*(9), 1158-1169. doi: 10.1111/j.1365-2702.2006.01473.x.

Andershed, B., & Werkander, C. (2007). Next of kin's feelings of guilt and shame in end-of-life care. *Contemporary Nurse, 27*(1), 61-72.

Assisted Living Federation of America. (2001). O*verview of the assisted living industry, 2001*. Fairfax, VA: Author.

Ball, M. M., Perkins, M. M., Whittington, F. J., Connell, B. R., Hollingsworth, C., King, S. V., & Combs, B. L. (2004). Managing decline in assisted living: The key to aging in place. *Journals of Gerontology. Series B, Psychological Sciences and Social Sciences, 59*(4), S202-212.

Baer, W., & Hanson, L. C. (2000). Families' perception of the added value of hospice in nursing homes. *Journal of the American Geriatrics Society, 48*(8).

Bern-Klug, M. (2009). A framework for categorizing social interactions related to end-of-life care in nursing homes. *The Gerontologist, 49*(4), 495-507.

Bern-Klug, M., & Forbes-Thompson, S. (2008). Family members' responsibilities to nursing home residents "she is the only mother I got." *Journal of Gerontological Nursing, 34*(2), 43-52.

Bernard, S. L., Zimmerman, S., & Eckert, J. K. (2001). Aging in place. In S. Zimmerman, P. D. Sloane, & J. K. Eckert (Eds.), *Assisted living: Needs, practices and policies in residential care for the elderly* (pp. 224-241). Baltimore, MD: Johns Hopkins University Press.

Biedenharn, P. J., & Normoyle, J. B. (1991). Elderly community residents' reactions to the nursing home: An analysis of nursing home related beliefs. *The Gerontologist, 31*(1), 107-115. doi: 10.1093/geront/31.1.107.

Blum, K., & Sherman, D. (2010). Understanding the experience of caregivers: A focus on transitions. *Seminars in Oncology Nursing*, *26*(4), 243-258.

Boelk, A.& Kramer, B. J. (2012). Advancing theory of family conflict at the end of life: A hospice case study. *Journal of Pain & Symptom Management*, *44*(5), 655-670.

Boockvar, K., Fishman, E., Kyriacou, C. K., Monias, A., Gavi, S., & Cortes, T. (2004). Adverse events due to discontinuations in drug use and dose changes in patients transferred between acute and long-term care facilities. *Archives of Internal Medicine, 164*, 545-50.

Breckenridge, J. P., Jones, D., Elliott, I., & Nicol, M. (2012). Choosing a methodological path: Reflections on the constructivist turn. *Grounded Theory Review: An International Journal, 1*(11). Retrieved from http://groundedtheoryreview.com/2012/06/01/choosing-a-methodological-path-reflections-on-the-constructivist-turn/.

Brown, J.D., & Furstenberg, F.F.. (1992). Restoring control: Empowering older patients and their families during health crisis. *Social Work in Health Care*, *17*(4), 81-101.

Caffrey, C., Sengupta, M., Park-Lee, E., Moss, A., Rosenoff, E., & Harris-Kojetin, L. (2012). Residents living in residential care facilities: United States, 2010. *NCHS Data Brief,* no 91. Hyattsville, MD: National Center for Health Statistics.

Caron C.D., & Bowers, B.J. (2003). Deciding whether to continue, share, or relinquish caregiving: Caregiving views. *Qualitative Health Research*, *13*, 1252-1271.

Cartwright, J., & Kayser-Jones, J. (2003). End-of-life care in assisted living facilities. *Journal of Hospice and Palliative Nursing, 5*(3), 143- 151.

Cartwright, J. C., Hickman, S., Perrin, N., & Tilden, V. (2006). Symptom experiences of residents dying in assisted living. *Journal of the American Medical Directors Association, 7*(4), 219-223.

Cartwright, J. C., Miller, L., & Volpin, M. (2009). Hospice in assisted living: Promoting good quality care at the end of life. *The Gerontologist, 49*(4), 508-516.

Centers for Disease Control and Prevention. (2010). *National survey of residential care facilities (NSRCF).* National Center for Health Statistics. Retrieved from www.cdc.gov/nchs/nsrcf.htm.

Centers for Disease Control and Prevention. (2013). *Aging in place*. Healthy Places Terminology. Retrieved from http://www.cdc.gov/healthyplaces/terminology.htm.

Chapin, R., & Dobbs-Kepper, D. (2001). Aging in place in assisted living: Philosophy versus policy. *The Gerontologist, 41*(1), 43-50.

Charmaz, K. (2000). Constructivist and objectivist grounded theory. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 509-535). Thousand Oaks, CA: Sage.

Chenitz, W. C., & Swanson, J. M. (1986). *From practice to grounded theory: Qualitative research in nursing*. Menlo Park, CA: Addison-Wesley

Cheek, J., & Ballantyne, A. (2001). Moving them on and in: The process of searching for and selecting an aged care facility. *Qualitative Health Research*, *11*(2), 221-237.

Chick, N., & Meleis, A.I. (1986). Transitions: A nursing concern. In A.I. Meleis (Ed.), *Transitions theory: Middle-range and situation-specific theories in nursing*. New York City, NY: Springer Publishing Company.

Cohen, D. J., & Crabtree, B. F. (2008). Evaluative criteria for qualitative research in health care: Controversies and recommendations. *Annals of Family Medicine, 6*(4), 331-339.

Coleman, E. A., Smith, J. D., Frank, J. C., Min, S., Parry, C., & Kramer, A. M. (2004). Preparing patients and caregivers to participate in care delivered across settings: The care transitions intervention. *Journal of the American Geriatrics Society, 52*, 1817-25.

Connors, A. F. Jr, Dawson, N. V., Desbiens, N. A., Fulkerson, W. J. Jr, Goldman, L., Knaus, W. A., & Ransohoff, D. (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). *JAMA, 274*(20), 1591-98.

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.

Creswell, J. W. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches* (3rd ed). Los Angeles, CA: Sage.

Davies, S. (2005). Meleis's theory of nursing transitions and relatives experiences of nursing home entry. *Journal of Advanced Nursing, 52*(6), 658-671.

Davis, A. J., Konishi, E., & Mitoh, T. (2002). The telling and knowing of dying: Philosophical bases for hospice care in Japan. *International Nursing Review, 49*, 2226-233.

Davis, C. G., Nolen-Hoeksema, S., & Larson, J. (1998). Making sense of loss and benefiting from the experience: Two construals of meaning. *Journal of Personality and Social Psychology, 75*(2), 561-574.

Davis, S., & Nolan, M. (2003). 'Making the best of things': Relatives' experiences of decisions about care-home entry. *Ageing & Society*, *23*, 429-450. doi: 10.1017/S0144686X03001259.

Degenholtz, H. B., Rhee, Y., & Arnold, R. M. (2004). Brief communication: The relationships between having a living will and dying in place. *Annals of Internal Medicine, 141*(2), 113-118.

Dellasega, C., & Mastrian, K. (1995). The process and consequences of institutionalizing an elder. *Western Journal of Nursing Research, 17*(2), 123-140.

Dixon, S., Fortner, J., & Travis, S.S. (2002). Barriers, challenges, and opportunities related to the provision of hospice care in assisted-living communities. *American Journal of Hospice & Palliative Care, 19*, 187-192.

Donaldson, M., & Field, M. J. (1998). Measuring quality of care at the end of life. *Archives of Internal Medicine, 158*, 121-128.

Dunmont, S., Turgeon, J. Allard, P., Gagnon, P., Charbonneau, C., & Vezina, L. (2006). Caring for a loved one with advanced cancer: Determinants of psychological distress in family caregivers. *Journal of Palliative Medicine*, *9*, 912-921.

Ellington, L., Cloyes, K., Berry, P., Thomas, N.T., Thum, N, Reblin, M. & Clayton M. (2013). Complexities for hospice nurses in supporting family caregivers: Opinions for U.S. thought leaders. *Journal of Palliative Medicine*, *16*(9), 1013-1018. doi: 10.1089/jpm.2013.0116.

Eagle, L.M., & de Vries, K. (2005). Exploration of the decision-making process for inpatient hospice admissions. *Journal of Advanced Nursing* 52:584-591.

Eaves, Y. D. (2001). A synthesis technique for grounded theory data analysis. *Journal of Advanced Nursing, 35*(5), 654-663.

Evans, W.G., Cutson, T.M., Steinhauser, K.E., & Tusley, J.A. (2006). Is there no place like home? Caregivers recall reasons for and experience upon transfer from home hospice to inpatient facilities. *Journal of Palliative Medicine, 9*, 100-110.

Ferguson, E., Lawrence, C., & Matthews, G. (2000). Associations between primary appraisals an life events while controlling for depression. *British Journal of Clinical Psychology*, 143-155.

Field, N. P., Bonanno, G. A., Williams, P., & Horwoitz, M. J. (2000). Appraisals of blame in adjustment in conjugal bereavement. *Cognitive Therapy and Research, 24*, 551-569. doi: 10.1023/A:1005514128798.

Fowler, F. J., Coppola, K. M., & Teno, J. M. (1999). Methodological challenges for measuring quality of care at the end of life. *Journal of Pain and Symptom Management, 17*(2), 114-119.

Funk, L., Stajduhar, K.I., Toye, C. Aoun, S., Grande, G.E., & Todd, C. J. (2010). Home-based family caregiving at the end of life: A comprehensive review of published qualitative research (1998-2008). *Palliative Medicine, 24*, 594-606.

Funk, L. M., Waskiewich, S., & Stajduhar, K. I. (2013). Meaning-making and managing difficult feelings providing front-line end-of-life care. *Omega, 68*(1), 23-43.

Gamino L. A., Sewell, K. W., & Easterline, L. W. (2000). Toward an adaptive model of grief. *Death Studies, 24*, 633-660. doi:10.1080/07481180050132820.

Gaugler, J. E., Anderson, K. A., Zarit, S. H., & Pearlin, L. I. (2004). Family involvement in nursing homes: Effects on stress and well-being. *Aging & Mental Health, 8*(1), 65-75.

Gaugler, J. E., & Kane, R. L. (2007). Families and assisted living. *The Gerontologist, 47*(Special Issue 3), 83-99.

Geary, C. R., & Schumacher, K. L. (2012). Care transitions: Integrating transition theory and complexity science concepts. *Advances in Nursing Science, 35*(3), 236-248.

Ghezeljeh, T. N., & Emami, G. (2009). Grounded theory: Methodology and philosophical perspective. *Nurse Researcher, 17*(1), 15-23.

Glaser, B.G. (1978). *Theoretical sensitivity: Advances in the methodology of grounded theory*. Mill Valley, CA: Sociology Press.

Glaser, B.G. (1998*). Doing grounded theory.* Mill Valley, CA: Sociology Press.

Glaser, B.G. (2001). *The grounded theory perspective: Conceptualization contrasted with description*. Mill Valley CA: Sociology Press.

Glaser, B. G. (2004). Remodeling grounded theory. *Forum: Qualitative Social Research 5*(2), article 4. Retrieved: http://www.qualitative-research.net/index.php/fqs/article/view/607/1315.

Glaser, B. G. [jillrhine] (2012, October 30). *Grounded theory is the study of a concept* [Video file]. Retrieved from: http://www.youtube.com/watch?v=OcpxaLQDnLk

Glaser, B.G with the assistance of Holton J. (2004). Remodeling grounded theory. *Forum Qualitative Sozialforschung [Forum: Qualitative Social Research]*, *5*(2), [80 paragraphs].

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago, IL: Aldine.

Glavin, P., Schieman, S., & Reid, S. (2011). Boundary-spanning work demands and their consequences for guilt and psychological distress. *Journal of Health and Social Behavior, 52*(1), 43-57. doi: 10.1177/0022146510395023

Gozalo, P., Teno, J. M., Mitchell, S. L., Skinner, J., Bynum, J., Tyler, D., & Mor, V. (2011). End-of-life transitions among nursing home residents with cognitive issues. *New England Journal of Medicine, 365*(13), 1212-1221.

Graham, C. L., Ivey, S. L., Neuhauser, L., (2009). From hospital to home: Assessing the transitional care needs of vulnerable seniors. *Gerontologist, 49*, 23-33.

Gruneir, A., Mor, V., Weitzen, S., Truchill, R., Teno, J., & Roy J. (2007). Where people die: A multilevel approach to understanding influences on site of death in America. *Medical Care Research and Review, 64*(4), 351-378.

Guba, E. G., & Lincoln, Y. S. (1989). *Fourth generation evaluation*. Newbury Park, CA: Sage.

Haley, W.E., LaMonde, L.A., Han, B. Burton, A.M., & Schnowetter, R. (2003). Predictors of depression and life satisfaction among spousal caregivers in hospice: Application of a stress process model. *Journal of Palliative Medicine*, *6*, 215-224.

Harstade, C.W., Roxberg, A., Andershed, B., & Brunt, D. (2012). Guilt and shame- a semantic concept analysis of two concepts related to palliative care. *Scandinanvian Journal of Caring Sciences*, *26*(4), 787-795. doi: 10.111/j.1471-6712.2012.0092.x.

Hawes, C., Phillips, C. D., Rose, M., Holan, S., & Sherman, M. (2003). A national survey of assisted living facilities. *The Gerontologist, 43*, 875-882.

Hebert R. S., & Schulz R. (2006). Caregiving at the end of life. *Journal of Palliative Medicine, 9*, 1174-1187.

Hudson, P., & Payne, S. (2011). Family caregivers and palliative care: Current status and agenda for the future. *Journal of Palliative Medicine*, *14*(7), 864-869. doi: 10.1089/jpm.2010.0413.

Hurley, S.L., Strupf, N., Barg, F., & Ersek, M. (2014). Not quite seamless: Transitions between home and inpatient hospice. *Journal of Palliative Medicine*, *17*(4), 428-434.

Idaho Department of Health and Welfare. (2013). *State only programs: Assisted living*. Retrieved from http://www.healthandwelfare.idaho.gov/Medical/LicensingCertification/StateOnlyPrograms/AssistedLiving/tabid/273/Default.aspx.

Institute of Medicine. (1990). *Medicare: A strategy for quality assurance*. Washington, DC: National Academy Press.

Institute of Medicine. (1997). *Preparing for the 21st century: Focusing on quality in a changing health care system*. Washington DC: National Academy Press.

Institute of Medicine. (1998). *Approaching death: Improving care at the end of life*. Retrieved: http://www.iom.edu/Reports/1998/Approaching-Death-Improving-Care-at-the-End-of-Life.aspx.

Institute of Medicine. (2008). Retooling for an aging America: Building the health care workforce. *Report Brief*, Washington (DC): National Academies Press; p. 257.

Jackson, J., Derderian, L, White, P., Ayotte, J, Firoini, J., et al., (2012). Family perspectives on end-of-life care. *Journal of Hospice & Palliative Nursing*, *14*(4), 303-311.

Jennings, B. (1997). *Ethics in hospice care: Challenges to hospice values in a changing health care environment.* New York, NY: Haworth Press.

Johnson, R. W., & Weiner, J. M. (2006). The retirement project. *The Urban Institute*. Retrieved: http://www.urban.org/UploadedPDF/311284_older_americans.pdf.

Jonasson, J. M., Hauksdottir, A. Nemes, S., Surkan, P. J. Valdimarsdottir, U., Onelov, E., & Steineck, G. (2011). Couples' communication before the wife's death to cancer and the widower's feelings of guilt and regret after the loss- a population-based investigation. *European Journal of Cancer*, *47*, 564-1570.

Jones, W. H., & Kugler, K. (1993). "Interpersonal correlates of the guilt inventory." *Journal of Personality Assessment, 61*, 246-258.

Kane, R. A., Chan, J., & Kane, R. L. (2007). Assisted living literature through May 2004: Taking stock. *The Gerontological Society of America, 47*(Special Issue 3), 125-140.

Kao, H.S., Travis, S.S., & Acton, G. (2004). Relocation to a long-term care facility: Working with patients and families before, during and after. *Journal of Psychosocial Nursing, 42*(3), 10-16.

Kaspers, P.J., Pasman, H.R., Onwuteaka-Philipsen, B.D., & Deeg, D.J.H., (2013). Changes over a decade in end-of-life care and transfers during the last 3 months of life: A repeated survey among proxies of deceased older people. *Palliative Medicine, 27*(6), 544-552.
.
Kass-Bartelmes, B. L., & Hughes, R. (2003). *Advance care planning: Preferences for care at the end of life. Agency for Health Care Quality: Research in Action #12*. Rockville, MD: Author. Retrieved: http://www.ahrq.gov/research/endliferia/endria.htm.

Kehl, K. A. (2006). Moving toward peace: An analysis of the concept of a good death. *Journal of Hospice & Palliative Medicine, 23*(4), 277-266.

Kehl, K. A., Kirchhoff, K. T., Kramer, B. J., & Hovland-Scafe, C. (2009). Challenges facing families at the end of life in three settings. *Journal of Social Work in End-of-Life & Palliative Care, 5*(3-4), 144-168. *doi: 10.1080/15524250903555080.*

Kellett, U. M. (1999). Transition in care: Family carers′ experience of nursing home placement. *Journal of Advanced Nursing, 29*(6), 1474-81.

Kelsey, S. G., Laditka, S. B., & Laditka, J. N. (August/September 2008). Transitioning dementia residents from assisted living to memory care units: A pilot study. *American Journal of Alzheimer Disease & Other Dementias, 23*(4), 355-362.

King, S., Collins, C. Given, B., & Vredevoogd (1991). Institutionalization of an elderly family member: Reactions of spouse and nonspouse caregivers. *Archives of Psychiatric Nursing, 5*(6), 323-330.

Kita, M., & Keiichi, I. (2012). The caregiving process of the family unit caring for frail older member at home: A grounded theory study. *International Journal of Older People Nursing, 8*(2), 149-158.

Kwon, S. Tae, Y. (2012). Nursing home placement: The process of decision-making and adaptation among adult children caregivers of demented parents in Korea. *Asian Nursing Research, 6*, 143-151.

Lewis-Beck, M. S., Bryman, A., & Liao, T. F. (2004). *The Sage encyclopedia of social science research methods*. Thousand Oaks, CA: Sage.

Levine, C., Halper, D., Peist, A., & Gould, D.A. (2010). Bridging troubled waters: Family caregivers, transitions, and long-term care. *Health Affairs*, *29*(1), 116-124. doi:1.377/hlthaff.2009.0520.

Lie, J., Stroebe, M., Chan, C., & Chow, A. Y.M. (2013). Guilt in bereavement: A review and conceptual framework. *Death Studies*, *38*(3), 165-171. doi: 10.1080/07481187.2012.738770.

Liken, M.A. (2001). Caregivers in crisis: Moving a relative with alzheimer's to assisted living. *Clinical Nursing Research*, *10*, 52-68.

Marco, C. A., Buderer, N., & Thum, S. D. (2005). End-of-life care: Perspectives of family members of deceased patients. *American Journal of Hospice and Palliative Medicine, 22*(1), 26-31. doi: 10.1177/104990910502200108.

Martin, V. B., & Gynnild, A. (2011). *Grounded theory: The philosophy, method, and work of Barney Glaser.* Boca Raton, FL: Brown Walker Press.

Martz, K. (2014). *Bereaved family member and hospice nurses perspective of transitions to and between residential care facilities at the end of life*. Unpublished dissertation: University of Utah, College of Nursing.

McMillan, S. (2005). Interventions to facilitate family caregiving at the end of life. *Journal of Palliative Medicine*, *8*(1), S-132-S-138.

Meadows, L. M., & Morse, J. M. (2001). Constructing evidence within the qualitative project. In J. M. Morse, J. M. Swanson, & A. J. Kuzel (Eds.), *The nature of qualitative evidence* (pp. 187-200). Thousand Oaks, CA: Sage.

Meleis, A.I. (Ed). (2010*). Transitions theory: Middle-range and situation-specific theories in nursing.* New York City, NY: Springer Publishing Company.

Meleis, A. I., Sawyer, L. M., Im, E. O., Hilfinger, Messias, D. K., & Schumacher, K. (2000). Experiencing transitions: An emerging middle-range theory. *Advances in Nursing Science*, *23*(1), 12-28.

Mezey, M., Dubler, N. N., Mitty, E., & Brody, A. A. (2002). What impact do settings and transitions have on quality of life at the end of life and the quality of the dying process? *The Gerontologist, 42*, 54-67.

Mitchell, S. L., Teno, J. M., Kiely, D. K., Shaffer, M. L., Jones, R. N., Prigerson, H. G., & Hamel, M. B. (2009). The clinical course of advanced dementia. *New England Journal of Medicine, 361*(16), 1529-38.

Mitty, E. L. (2004). Assisted living: Aging in place and palliative care. *Geriatric Nursing, 25*(3), 149-156, 163. doi: 10.1016/j.gerinurse.2004.04.019.

Mitty, E., & Flores, S. (2008). Aging in place and negotiated risk agreements. *Geriatric Nursing, 29*(2), 94-101.

Mitty, E., & Flores, S. (2009). There's no place like home. *Geriatric Nursing, 30*(2), 126-129. doi: 10.1016/j.gerinurse.2009.01.004.

Mizota, Y., Ozawa, M., & Inoue, Y. (2006). Psychosocial problems of bereaved families of HIV-infected hemophiliacs in Japan. *Social Science & Medicine, 62*(10) 2397-410.

Mollica, R. L. (2008). Trends in state regulation of assisted living. *Generations, 32*(3), 67-70.

Mollica, R., & Jenkens R. (2001). *State assisted living practices and options: A guide for state policymakers.* Portland, ME: National Academy for State Health Policy.

Morse, J.M. (1999). The armchair walkthrough [Editorial]. *Qualitative Health Research, 9*(4), 435-436.

Morse, J.M. (2001). Using shadowed data. *Qualitative Health Research, 11*(3), 291-292.

Morse, J. M. (2001). Situating grounded theory. In R. S. Schreiber & P. N. Stern (Eds.), *Using grounded theory in nursing* (pp. 1-15). New York, NY: Springer.

Morse, J. M. (2007). Sampling in grounded theory research. In T. Bryant & K. Charmaz (Eds.), *Handbook of grounded theory* (pp. 229-244). London, UK: Sage.

Morse, J. M. (2010). The praxis theory of suffering. In J. B. Butts, & K. L. Rich (Eds.), *Philosophies and theories in advanced nursing practice* (pp. 569–602). Sudbury, MA: Jones & Bartlett.

Morse, J. M. (2012). The implications of interview type and structure in mixed method designs. In J. F. Gubrium, J. A. Holstein, A. B. Marvasti, & K. D. McKinney (Eds.), *Sage handbook of interview research* (2nd ed.) (pp.280-310). Thousand Oaks, CA: Sage.

Morse, J. M., Stern, P. N., Corbin, J., Bowers, B., Charmaz, K., & Clarke, A. E. (2009*). Developing grounded theory: The second generation*. Walnut Creek, CA: Left Coast Press.

Munn, J. C., Hanson, L. C., Zimmerman, S., Sloane, P. D., & Mitchell, C. M. (2006). Is hospice associated with improved end-of-life care in nursing homes and assisted living facilities? *Journal of the American Geriatrics Society, 54*(3), 490-495.

National Center for Assisted Living. (2010). *Facts and trends: The assisted living sourcebook*. Washington, DC: Author.

National Hospice and Palliative Care Organization. (2013). NHPCO Facts and Figures Retrieved from http://www.nhpco.org/sites/default/files/public/Statistics_Research/2013_Facts_Figures.pdf

Naylor, M. D., Stephens, C., Bowles, K. H., & Bixby, M. B. (2005). Cognitively impaired older adults: From hospital to home. *American Journal of Nursing, 105*, 52-61.

Nolan, M., & Dellasega, C. (2000). 'I really feel I've let him down': Supporting family carers   during long-term care placement for elders. *Journal of Advanced Nursing*, *31*(4), 759-767.

Oleson, M., & Shadlick, K.M. (1993). Application of Moos and Schaefer's (1986) model to nursing care of elderly persons relocating to a nursing home. *Journal of Advanced Nursing*, *18*, 479-485.

Pearlin, L., Mullan, J., Semple, S., & Skaff, M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *Gerontologis*t, *30*, 583-59.

Penrod, J. & Dellasega, C. (2001). Perspectives of placement: Implications for practice. *Journal of Gerontological Nursing*, *11*, 29-36.

Penrod, J., Hupcey, J. E., Shipley, P. Z., Loeb, S. J., & Baney, B. (2012). A model of caregiving through the end of life seeking normal. *Western Journal of Nursing Research*, *34*(2), 174-193.

Pierce, S. F. (1999). Improving end-of-life care: Gathering suggestions from family members. *Nursing Forum, 34*(2), 5-14.

Port, C. L., Zimmerman, S., Williams, C. S., Dobbs, D., Preisser, J. S., & Williams, S. W. (2005). Families filling the gap: Comparing family involvement for assisted living and nursing home residents with dementia. *The Gerontologist, 45*(Special Issue 1), 87-95.

QSR International Pty Ltd. Version 19 (2011). NVivo qualitative data analysis software.

Reed, J., & Payton, V. (1996). Constructing familiarity and managing the self: Way of adapting to life in nursing and residential homes for older people. *Ageing and Society, 16*(5), 543-560.

Read, T., & Wuest, J. (2007). Daughters caring for dying parents: A process of relinquishing. *Qualitative Health Research, 17*, 932-943.

Rich, S. E., Williams, C. S., & Zimmerman, S. (2009). Concordance of family and staff member reports about end of life in assisted living and nursing homes. *The Gerontologist, 50*(1), 112-20.

Ryan, A. (2002). Transitions in care: Family carers' experiences of nursing home placement. *Nursing Times Research, 7,* 324-34.

Ryan, A.A., & Scullion, H.F. (2000). Family and staff perception of the role of families in nursing homes. *Journal of Advanced Nursing, 32*(3), 626-34.

Schreiber, R. S., & Stern, P. N. (2001). *Using grounded theory in nursing*. New York, NY: Springer.

Schulz, R., Belle, S. H., Czaja, S. J., McGinnis, K. A., Stevens. A., & Zhang, S. (2004). Long-term care placement of dementia patients and caregiver health and well-being. *JAMA, 292*(8), 961-967. doi:10.1001/jama.292.8.961.

 Schumacher, K. L., & Meleis, A. (1994). Transitions: A central concept in nursing. *Journal of Nursing Scholarship, 26*(2), 119-127.

Shield, R.R.,Wetle,T.,Teno, J., Miller, S.C., & Welch, L.C. (2010). Vigilant at the end of life: Family advocacy in the nursing home. *Journal of Palliative Medicine, 13* (5), 579-89.   doi: 10.1089/jpm.2009.0398.

Sinding, C., & Aronson, J. (2003). Exposing failures, unsettling accommodations: Tensions in interview practice. *Qualitative Research, 3*(1), 95-117.

Sloane, P. D., Zimmerman, S., Hanson, L., Mitchell, C. M., Riedel-Leo, C., & Custis-Buie, V. (2003). End-of-life care in assisted living and related residential care settings: Comparison with nursing homes. *Journal of the American Geriatrics Society, 51*(11), 1587-1594. doi: 10.1046/j.1532-5415.2003.51511.x.

Span, P. (2012, April 18). Where the oldest die now. *New York Times*, Retrieved from: http://newoldage.blogs.nytimes.com/2012/04/18/where-the-oldest-die-now/?ref=health.

Spross, J. (1996). Coaching and Suffering: The role of the nursing in helping people face illness. In B.R. Ferrell (Ed.), *Suffering* (pp. 282-207). Sudbury, MA: Jones and Bartlett Publishers.

Stajduhar, K.I., Funk, L., Toye, C., Grande, G.E., Aoun, S., & Todd, C.J. (2010). Part 1: Home-based family caregiving at the end of life: A comprehensive Review of published quantitative research (1998-2008*). Palliative Medicine*, *24*(6), 573-593. doi: 10.1177/0269216310371412.

State of Idaho Legislature. (2012). Idaho Statue Title 39 Health and Safety. Retrieved from: www.legislature.idaho.gov/idstat/Title39/T39CH33SECT39-3307.htm.

Stern, P. N., & Porr, C. J. (2011). *Essentials of accessible grounded theory*. Walnut Creek, CA: Left Coast Press.

Stone, L. J., & Clements, J. A. (2009). The effects of nursing home placement on perceived levels of caregiver burden. *Journal of Gerontological Social Work, 52*(3), 193-214. doi: 10.1080/01634370802609163.

Strang, V. R., Koop, P. M. Dupuis-Blanchard, S., Nordstrom, M., & Thompson, B. (2006). Family caregivers and transition to long-term care. *Clinical Nursing Research, 15*(1), 27-45. doi:10.1177/1054773805282356.

Strauss, A. L., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2nd ed). Thousand Oaks, CA: Sage.

Stuifbergen, M. C., & Van Delden, J. J. M. (2011). Filial obligations to elderly parents: A duty to care? *Medical Health Care Philosophy, 14*(1), 63-71.

Surkan, P. J., Kreicbergs, U., Valdimarsdottir, U., Nyberg, U., Onelov, E., Dickman, P. W., & Steineck, G. (2006). Perceptions of inadequate health care and feelings of guilt in parents after the death of a child to a malignancy: A population-based long-term follow-up. *Journal of Palliative Medicine, 9*(2), 317-331.

Sussman, T., & Dupuis, S. (2012). Supporting relative's move into long-term care: Starting point shapes family members experiences. *Canadian Journal on Aging/La Revue canadienne du vieillissement, 31*(4), 395-410.

Tangney, J. P. (1996). Conceptual and methodological issues in the assessment of shame and guilt. *Behaviour research and therapy, 34*(9), 741-754.

Tangney, J. P., Miller, R. S., Flicker, L., & Barlow, D. H. (1996). Are shame, guilt, and embarrassment distinct emotions? *Journal of Personality and Social Psychology, 70*(6), 1256.

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 and Symptom Management, 22*(3), 738-751. doi: 10.1016/s0885-3924(01)00335-9.

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. *JAMA, 291*(1), 88-93. doi: 10.1001/jama.291.1.88.

Theixos. H. (2013). Adult children and eldercare: The moral considerations of filial obligations. *Michigan Family Review*. Retrieved from: http://quod.lib.umich.edu/m/mfr/4919087.0017.105?rgn=main;view=fulltext.

Tilghman-Osborne, C., & Cole, D. A. (2010). Definition and measurement of guilt: Implications for clinical research and practice. *Clinical Psychology Review*, *30*, 436-546. doi: 10.1016/j.cpr.2010.03.007.

Transitions [Def. 1a]. (n.d.). In *Merriam Webster.* Retrieved June 14, 2014, from http://www.merriam-webster.com/dictionary/citation.

Volpin, M. (2011). *The experiences of family caregivers of assisted living residents enrolled in hospice* (doctoral dissertation). Oregon Health & Science University, Portland, OR.

Waldrop, D., Kramer, B., Stretny, J. A., Milch, R. A., & Finn, W. (2005). Final transitions: Family caregiving at the end of life. *Journal of Palliative Medicine, 8*(3), 623-638.

Waldrop, D.P., & Meeker, M. (2011). Crisis in caregiving: When home-based end-of-life care is no longer possible. *Journal of Palliative Care*, *27*(2), Summer, 117-125.

Weinberg, N. (1994). Self-blame, other blame, and desire for revenge: Factors in recovery from bereavement. *Death Studies*, *18*(6), 583-593.

Weinberg, N. (1995). Does apologizing help? The role of self-blame and making amends in recovery from bereavement. *Health and Social Work, 20*(4), 294-9.

Wilkes, L., Jackson, D., & Vallido, T. (2008). Placing a relative into a nursing home: Family members' experiences after the move. A review of the literature. *Geriaction*, *26*(1), 24-29.

Williams, S. W. Zimmerman, S., & Williams, C. S. (2012). Family caregiver involvement for long-term care residents at the end of life. *Journal of Gerontology Series B: Psychologoical Sciences and Social Sciences, 65*(5), 595-604. doi:10.1093/gernonb/gbs065.

Wilson, K. B. (2007). Historical evolution of assisted living in the United States, 1979 to present. *The Gerontologist, 47*(Special Issue 3), 8-22.

Wuest, J. (2000). Repatterning care: Women's proactive management of family Caregiving demands. *Health care for Women International*, *21*, 393-411.

Wuest, J., & Hodgins, M. (2007) (Jul-Sep). The effects of past relationship and obligation on health and health promotion in women caregivers of adult family members. *Advances in Nursing Science*, *30*(3), 206-20.

Ylitalo, N., Valdimarsdottir, U., Onelov, P, Dickman, P.W., & Steineck, G. (2008). Guilt after the loss of a husband to cancer: Is there a relation with the health care provided? *Acta Oncolgica*, *27*, 870-878.

Zimmerman, S., Sloane, P. D., & Eckert, J. K. (2001). *Assisted living: Needs, practices, and policies in residential care for the elderly*. Baltimore, MD: Johns Hopkins University Press.