

THE EXPERIENCES OF FAMILY CAREGIVERS OF ASSISTED LIVING
RESIDENTS ENROLLED IN HOSPICE

By

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ABSTRACT

TITLE: The Experiences of Family Caregivers of Assisted Living
Residents Enrolled in Hospice

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RATIONALE: Assisted Living (AL) is a rapidly growing housing option. Increasingly, residents are staying in AL facilities until death. The best way to provide end-of-life care in this congregate living environment is unclear. Family involvement can be key to residents' ability to stay in their AL home, but research regarding the family caregiver's role and activities is limited. Understanding the challenges and needs of these family caregivers can provide insight into how to best support them and by extension improve the quality of death for the family members residing in assisted living.

PURPOSE: The purpose of this study was to describe the experiences of family caregivers providing care to their family members living in assisted living and approaching death.

METHOD: An exploratory, descriptive, qualitative design was used. Ten participants, family members of seven AL residents, took part in this study, which utilized semi-structured interviews and participant observation for a total of 13 interviews and 14 observations. Data analysis involved: 1) transcribing interviews; 2) reading transcripts; 3) coding salient data; 4) identifying themes and categories; 5) creating a model.

RESULTS: An overarching goal was found to be a framing and motivating force for the family caregivers' efforts. The family caregivers' overarching goal was to maintain the

AL placement until the care recipient's death. In order to achieve that goal, family caregivers engaged in a continuous process of monitoring the care recipient's needs and how well those needs were being met through a combination of AL, hospice, and, to a lesser degree, family involvement in care. The family caregivers responded to any unmet needs of the care recipient by either managing the care provided by others, or by supplementing the care with direct care activities themselves. The intensity of involvement in care was mediated by the competing demands on the family caregiver and on the quality of his/her relationship with the care recipient. As the care recipient's needs changed over time, the family caregiver's involvement in care also changed, either increasing or decreasing in intensity, depending on their appraisal of the care recipient's changing needs.

IMPLICATIONS: Because much of family caregiver response is based on overarching goals and perceptions, it is important that communication be ongoing between the family and professional caregivers regarding the care recipient's needs, prognosis, and ability to maintain placement. A better understanding of what facilities and hospice personnel can and will do can help family caregivers in planning their own involvement in care.

LIMITATIONS: Limitations of this study included the lack of ethnic diversity in the sample, potential for recruitment bias related to the reliance on hospice personnel who may have acted as "gatekeepers" when choosing which family caregivers to approach, and the inability to observe or conduct follow-up interviews with all the participants.

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Chapter 1: Introduction

The aging of the U.S. population will have a far-reaching effect on many aspects of American life, culture, and institutions. Already changing is where and how people live—and die. Illustrative of this shift is the decrease in nursing home (NH) use and the rapid expansion of assisted living (AL) facilities (Ball et al., 2004; Federal Interagency Forum on Aging-Related Statistics, 2006). Since AL facilities are less expensive and generally less institutional than NHs, older adults are increasingly choosing them over NHs. More and more of these adults are staying in their AL homes until death; nationally, one-third of residential care/assisted living residents remain in their residence until death, with an annual turnover rate due to death between 16% and 28% (Cartwright, Hickman, Perrin, & Tilden, 2006; Dobbs, Hanson, Zimmerman, Williams, & Munn, 2006).

The American hospice model was originally developed for home-based care of terminally ill persons with the family providing hands-on care. From this origin, hospice services have expanded to other settings, first into nursing homes, and then, more recently, into other congregate residential settings, including AL. Despite this expansion, it is unclear how hospice care is best provided in an environment that is not a traditional home (where there is no single individual who is dedicated to the dying individual's support and care) nor a nursing home (with licensed staff available 24 hours a day). Family involvement appears to be key in making it possible for residents to stay in AL facilities even when their condition declines (Gaugler & Kane, 2007), but there is very limited research regarding the interactions among the AL resident, family members, and hospice and assisted living staff, and how these interactions affect the AL resident's

dying experience. Research investigating the specific role(s) that families play and the challenges that they experience is extremely limited. The purpose of this study is to explore the experience of family caregivers of assisted living facility residents enrolled in hospice. This study explored the factors that make it possible for some family caregivers to provide these services, the challenges that they face when providing care, and the positive and negative impacts of providing such care. The knowledge gleaned from this study may provide information useful for the development of policy and programs to support good end-of-life care in AL.

Background

Demographic Changes

In 2000, 35 million people in the United States were over age 65, and 4.2 million of those individuals were over age 85. Current projections are that these numbers will increase to 40.2 million and 6.1 million respectively by 2010, and to 54.6 million and 7.3 million respectively by 2020. This represents a 48% increase in individuals over 65 and a 43% increase in individuals over 85 between 2005 and 2020 (Houser, Fox-Grage, & Gibson, 2006; Federal Interagency Forum on Aging-Related Statistics, 2006). Despite this growing older population, nursing home use has declined, from 200 per 1,000 for individuals 85 and older in 1985 to 183 per 1,000 in 1999 (Federal Interagency Forum on Aging-Related Statistics, 2006). At the same time, there has been an increase in new living environments for older adults who can no longer live in their own homes but do not want to live in a nursing home. These environments include residential care, board and care facilities, personal care homes, sheltered care, adult foster homes, assisted living

facilities, and continuing care retirement communities. These settings range from 4–5 residents to 100–200 residents. Growth in residential care has been phenomenal. For example, residential care beds increased from 998,630 beds in 2000 to 1,026,397 beds in 2002 (Harrington, Chapman, Miller, Miller, & Newcomer, 2004). The fastest growing residential care setting for frail older adults is the assisted living facility, which saw a 14.5% increase in capacity between 2000 and 2001 (Ball et al., 2004). As this number continues to increase, so will the number of older adults who need terminal care within this setting.

Family Caregiving

Estimates are that more than 50 million people provide care for a chronically ill, disabled, or aged family member in any given year (National Family Caregivers Association, 2002). Most of these people are middle-aged women providing care for a mother who does not live with them. Approximately 30% of family caregivers caring for seniors are themselves over the age of 65. Family caregiving does not end when an individual moves out of a private home into another residential setting. Studies show that families continue to feel responsible for their loved one's well-being and continue to be very involved in their lives, visiting often and continuing to provide care and assistance (Friedemann, Montgomery, Maiberger, & Smith, 1997; Gaugler, 2005; Ross, Carswell, & Dalziel, 2001). Studying the experience of family caregivers and the impact caregiving has on their lives can lead to better understanding caregivers' needs and developing methods to help them to manage this role. Additionally, assisting family caregivers to

successfully care for and support their frail older adults allows the older adult to live in the least restrictive environment possible.

Estimates of the annual monetary value of services provided by family caregivers range from a low of \$205 billion (29 million caregivers at \$6.64/hr.) to a high of \$800 billion year (41 million caregivers at \$18.22/hr.) (Houser & Gibson, 2008). It is hard to conceptualize the impact on government, governmental services, and the economy in general if this cost shifted to the public sector.

With the aging of the population, the need for family caregivers will continue to increase. The population of people over 65 is expected to increase by 2.3% annually, but the number of family members available to care for them will increase by only 0.8% per year. Besides the financial cost, informal caregiving has been shown to increase morbidity and mortality for those providing care (Schulz & Beach, 1999; *Statistics on Family Caregivers and Family Caregiving*, 2002). The question is then raised, how can family caregiving be provided without entailing such high costs in caregiver health? Clearly, the more we can support family caregivers, the less government support is necessary, and the less cost is entailed in terms of lost wages and increased health costs for the family caregivers.

While moving a family member to a residential setting changes the nature and source of stress, there is little to indicate that such a move eliminates burden for family caregivers (Friedemann et al., 1997). Although family presence in long-term care has been documented, there is limited information available regarding the nature of this involvement, or empirical data specifically from the family caregiver perspective.

Research of any kind on family caregiving in AL facilities is particularly scarce. This lack of knowledge limits our ability to support these family caregivers or understand the cost of this care to the caregivers and society.

Assisted Living

Assisted living facilities play an ever-increasing role in where and how frail older adults live. Developed to maximize autonomy and privacy, AL was originally designed and staffed to provide assistance to its residents with activities of daily living (ADLs) and instrumental activities of daily living (IADLs). These services are primarily provided by unlicensed assistive personnel for people with stable and predictable conditions. Assisted living was also envisioned as an environment that could accommodate an individual's changing abilities and allow them to stay in the AL setting for as long as they desired. To meet this goal, the expectation was that AL would provide additional appropriate services (either directly or through use of outside resources) to manage the effects of chronic disease or disability, including end-of-life palliative care (Wilson, 2007).

Regulation of AL facilities is at the state level, leading to great variation in policies regarding such issues as admission and discharge criteria, staffing requirements, and the type and nature of services provided. The vision of aging in place while experiencing increasing decline and disability has quickly become problematic, particularly in light of various state regulations and reimbursement rules (Wilson, 2007). Some states, for example, have strict regulations regarding admission and retention that force residents to relocate if their care needs reach a specified level. The lack of industry-wide clarity regarding the definition and philosophy of assisted living has added to

consumer confusion regarding the scope of services that assisted living facilities could and should be offering in terms of services and support (Dixon, Fortner, & Travis, 2002). The issue becomes more complex as residents age and become more functionally impaired, resulting in more complex health issues and higher care needs. Realizing the goal of aging in place requires a balancing act between the requirements of the resident, the capacity and approach of the facility, and the ability to engage other professional and personal resources (Ball et al., 2004).

While the AL industry generally has retreated from its earlier stance of promoting aging in place, some states such as Florida, New Jersey, and Oregon specifically encourage it (Mitty, 2004). Furthermore, many residents and families have stated their desire for AL residents to die in their AL homes (Cartwright & Kayser-Jones, 2003). The challenge is how to meet these personal and policy goals in a setting that provides limited clinical management of complex healthcare needs.

Assisted living residences are considerably less expensive than nursing homes. The average monthly cost for a private, one-bedroom AL unit is \$3,300 a month, or \$39,600 a year. This compares to the average annual cost for a private room (single occupant) in a nursing home of \$81,030 (Genworth Financial, 2012). While most AL facilities are private pay, there are approximately 55,000 Medicaid-eligible residents in 41 states who receive personal and health-related benefits. Additionally, 33 states cover eligible AL residents who require NH level of care under Home and Community-Based Services waivers (Mitty, 2004). The combination of increased use, desire to avoid nursing home placement, and cost differential mean that more people with chronic,

terminal diseases will likely enroll in hospice and attempt to stay in their AL home until death. Discovering what is involved in the process of providing good hospice care in AL facilities will help direct the development of approaches to end-of-life care that increase the likelihood that AL residents can experience a good death at “home.”

Hospice in Assisted Living

Hospice care is a comprehensive program of care for patients and families facing a terminal illness and a prognosis of less than six months. Hospice generally is not a place, but an approach to care that provides a range of supportive services to dying individuals and their families. Historically, the majority of hospice services were provided to persons with cancer in private homes, with family members providing the bulk of the day-to-day care. In 1985, Medicare officially allowed hospice care to be provided in nursing homes. Despite this, regulations, logistics, and resistance by nursing homes have made acceptance of hospice in nursing homes a slow and limited process (Blevins & Deason-Howell, 2002; Ersek & Wilson, 2003; Miller & Mor, 2004; Travis et al., 2002).

More recently, hospice services have expanded to include persons living in assisted living and other residential care settings: in 2006 4.6% of hospice care was provided in residential care facilities (National Hospice and Palliative Care Organization, 2007). The introduction of hospice into AL improves the potential for AL residents who so desire to die in their AL home. However, it also provides a challenge to both the hospice agency and the assisted living facility, as the AL setting does not automatically

include someone who directs and provides the bulk of the actual care, such as is generally provided by family members in private homes or by nursing staff in nursing homes.

Assisted living has a mixed record for utilizing hospice or allowing hospice-enrolled residents to stay in their facility. Many states require special permission for admitting or retaining residents who need hospice care (National Senior Citizens Law Center, 2007). The complicated nature of providing hospice in assisted living is further indicated by the responses of trade and professional organizations. For example, the Assisted Living Federation of America (ALFA) issued a policy brief in May 2007 supporting the right of persons enrolled in hospice to either move into or remain in assisted living if they wish, so long as their provider, family/resident and physician all agree (Bersani, 2007). Furthermore, ALFA created a “toolkit” on hospice and AL that it released in July 2007 (Webster, 2007). This toolkit provides information aimed at helping consumers, assisted living providers, and hospice providers to make decisions around, and provide care for, an AL resident at end of life.

The Wisconsin division of the Association of Homes and Services for the Aging (AHSa) also developed a toolkit designed to help nursing homes and AL facilities to access hospice services. The “Hospice and Nursing Home/Assisted Living Contracting Toolkit” contains information about regulatory issues, tips for evaluating hospices, and templates for creating agreements between hospices and AL facilities (AHSa, 2008). Clearly, delivering hospice care in assisted living is a complex process that requires an adjustment of both the traditional hospice and assisted living models of care. Even though the acuity and care needs of AL residents may be similar to those of nursing home

clients, the available resources and logistics can be greatly different (Dixon et al., 2002). Therefore, we need to understand what factors facilitate or obstruct the provision of hospice care in AL.

Assisted Living, Family Caregiving, and Hospice

A common misconception of AL is that when a frail older adult moves to a residential setting that provides 24-hour care, the care responsibilities rendered by family caregivers are replaced by the services provided by the facility. This idea has been refuted by recent studies that have enumerated the range of assistance that family caregivers provide to relatives living in assisted living and other care settings. Gaugler and Kane (2007) define three domains of care that family often provide: *personal care*, which covers activities of daily living; *instrumental care* such as shopping, money management and providing transportation, and *socioemotional support*, which includes general social interactions and activities. Gaugler and Kane (2007) also mention other important areas of care provided by families, including monitoring care, providing information to care staff, directing formal care, and advocating for their family member. Furthermore, it has been found that family involvement in these and other areas are key to residents being able to stay in their assisted living residence (Cartwright & Kayser-Jones, 2003).

While some of the physical burden for family caregivers may be eased when their relative moves into an assisted living facility, the family caregivers still experience financial, social, and emotional strain (Port et al, 2005). This is particularly true as an AL resident nears the end of their life and requires more complex care (Gaugler & Kane,

2007). Part of the problem faced by family caregivers appears to be a lack of understanding on their part as to what AL can and cannot provide for residents who wish to die in the AL facility. In addition, family caregivers often lack preparation for the end-of-life care planning decisions that need to be made (Dixon et al., 2002). At this time, there is little information as to how caring for someone in assisted living at the end of their life affects the family caregivers involved. In addition, we have little understanding of the role that family caregivers play in supporting older relatives in AL through the end of their lives.

A combination of factors gave the impetus for this study and the development of its specific aims. These factors include: the increase in the age and frailty of older Americans; the increased use of assisted living as a residential setting for frail older persons; the increased number of people dying in AL; the increased use of hospice services in AL; the role family caregivers play in end-of-life care for AL residents (which some believe makes it possible for them to stay in their AL home until death); and the lack of knowledge of the experience of family caregivers who provide end-of-life care for a relative in AL. All of these factors led to focusing this study on an exploration of the experience of family caregivers of assisted living facility residents enrolled in hospice. This study addressed the following aims:

1. Describe the various roles that family caregivers play in end-of-life care for older adults enrolled in hospice who live in assisted living facilities.

2. Describe the expectations that family caregivers have for themselves, the assisted living facility and hospice personnel involved in providing end-of-life care for older adults enrolled in hospice.

Significance to Nursing

Hospice care is largely delivered and managed by registered nurses (RNs). Currently, about 70% of all assisted living facilities employ an RN or LPN, although this number is expected to grow (Mitty, 2003). In some states, such as Oregon, all assisted living facilities must have access to a registered nurse. This regulation generally translates into RN assessment, oversight, and management of residents. As the U.S. population continues to age, and AL continues to grow, more individuals will die in AL facilities, and more of them will be enrolled in hospice. By expanding our knowledge and understanding of what families do for their family members dying in an AL facility, and what that experience means to them, this study can have a direct impact on nursing practice for both hospice and AL nurses. Increased knowledge of the needs and abilities of AL residents and their family caregivers, and of how best to communicate with and support dying residents and their family caregivers, may improve AL residents' ability to stay in their desired environment until death. It may also be possible to improve AL end-of-life care for AL residents and mitigate some of the negative consequences experienced by their family caregivers.

A better understanding of the context, concerns, and needs of AL residents and their family caregivers at end of life can also inform state and national policy regarding end-of-life care for AL residents. The lack of clarity regarding the aspects of care that are

regulated by the government and also subject to the individual policies of AL facilities creates confusion and often provides contradictory information for consumers and healthcare providers. Clear, consistent policies from overseeing bodies will help bring all the players onto the same page and can provide guidance for ensuring that AL residents receive the best possible care, in the best setting, at end of life. It is essential that these policies take into account the needs of family members who support older relatives as they live and die in assisted living.

The field of assisted living research is nascent and, as evidenced by the numerous calls for future research in the special issue of *The Gerontologist* (Gaugler & Kane, 2007; Hyde, Perez, & Forester, 2007; Kane, Wilson, & Spector, 2007; Kane & Mach, 2007), has many unexplored areas of enquiry that affect health and health care delivery. There is a need for more empirical data regarding end-of-life care in assisted living. In order to develop policy and improve nursing practice for AL residents and for aging in place, it is imperative that we understand the roles and experiences of family caregivers while supporting a family member dying in assisted living.

Chapter 2: Review of the Literature

A Young Field

When a phenomenon is relatively new, it follows that the science that examines the phenomenon will also be in its early stages. In a literature search aimed at assessing the state of the science regarding end-of-life research, George (2002) found that 90% of the articles related to end of life were published after 1990. Information about the end-of-life experience or what is important at end of life in long-term care settings is extremely limited. Much of the research has focused on community-dwelling individuals, and has looked at disease-specific populations, most frequently cancer (Munn & Zimmerman, 2006).

Assisted living (AL) as a named concept has only been in existence since 1981. A recent, broadly designed literature review of AL spanning the years 1989 to May 2004 found only 120 manuscripts describing studies performing primary or secondary data collection (Kane, Chan, & Kane, 2007). More specifically, a literature review of families in AL by Gaugler and Kane (2007) found 62 manuscripts appropriate for inclusion. These papers fit in the categories of: family structure in AL; types and predictors of family involvement in AL; or family-related outcomes. When I did a literature search on end of life in AL, searching Medline, CINAHL and PsychINFO, as well as reviewing the references of all relevant articles found, I was able to identify only five articles representing research studies of end-of-life care in assisted living (Ball et al., 2004; Cartwright & Kayser-Jones, 2003; Cartwright, Hickman, Perrin, & Tilden, 2006; Dixon, Fortner, & Travis, 2002; Munn & Zimmerman, 2006) and one literature review and

analysis aimed at identifying the research needs related to quality end-of-life care and quality of dying for vulnerable older adults in various settings, including AL (Mezey, Dubler, Mitty, & Brody, 2002). Of the five research articles, one looked at end of life only peripherally as the natural end-point of aging in place (Ball et al., 2004), and one was a comparison of end-of-life care in nursing homes and assisted living/residential care settings (Munn & Zimmerman, 2006).

Because of the limited research available on assisted living, a common approach is to look to analogous settings, most commonly long-term care in nursing homes. It is possible to glean meaningful information from such a review as long as the differences and similarities between the two settings are kept in mind.

The purpose of this review of the literature is to explore how hospice care is delivered in assisted living, to examine how family caregivers are involved with AL residents at end of life, and to examine how end-of-life care is perceived and engaged in by family members of AL residents. Because the literature related to the AL setting is limited, studies in nursing homes (NH) will also be included and compared. Criteria for inclusion in this review were: 1) research-based articles that were set in either assisted living facilities or nursing homes, or that compared AL facilities and NHs; and 2) included either family caregiving or end of life. Tables A1 through A6 in Appendix A summarize the relevant findings. In this review, I will first describe the phenomenon of assisted living in more depth, and will then analyze the empirical results related to aging in place and end of life (including hospice) in AL. I will then examine family caregivers in NH and AL, focusing on family caregiver roles and expectations, and family

caregivers of NH and AL residents at end of life, focusing on family caregiver roles, and the barriers and facilitators to family caregiving of NH and AL residents at the end of life. Finally, I will summarize the major findings and identify areas where further research is needed.

Assisted Living

Definition and History

Assisted living facilities are a type of congregate housing designed for adults who do not need the level of care provided in a nursing home, but who need help to live independently and desire a setting that allows a higher level of autonomy, choice, and privacy (Dixon et al., 2002; Port et al., 2005). AL facilities are similar to nursing homes in that both settings serve a generally frail, elderly, resident population with multiple comorbidities and variable cognitive impairment (Cartwright & Kayser-Jones, 2003; Dixon et al., 2002); both have high resident to staff ratios and have limited or no medical provider presence; and both have residents who stay in the environment for an indefinite period of time. Both ALs and NHs may allow hospice to be brought in as an outside resource. Assisted living differs from nursing homes in that AL staff generally has minimal training and little or no certification, and there tends to be a dearth of licensed health care professionals (such as physical therapists, occupational therapists, and social workers) at an AL facility. Additionally, clinical staffing at an AL facility may be restricted to the LPN level, and may only be available for limited hours a week. AL and NH facilities differ from a regulatory perspective; while NHs are federally regulated, AL facilities are regulated on a state-by-state basis, with state definitions of assisted living

varying widely. Fiscally, the majority of NHs are Medicare and Medicaid certified; only a minority of AL facilities accepts Medicaid and the majority of residents are private-pay.

Assisted living facilities were developed in Oregon in 1981 as a housing option for older adults and have since expanded to every state in the United States. Criteria for admission generally include stable health and not needing 24-hour nursing care. In some states, exclusion criteria are fairly strict and may disallow a resident for being bed-bound, incontinent, or dependent in ambulation; having pressure ulcers; needing artificial feeding or hydration; or being dependent on a ventilator (Dixon et al., 2002). While some assisted living facilities have nursing staff on site, others contract with outside home health agencies for nursing services. Often, packages that include a range of services for additional costs are available.

Assisted living classification schema. One of the complicating factors in carrying out research in assisted living is the lack of commonly accepted definitions, despite early attempts to create a uniformly accepted concept. One of the first attempts to define AL occurred in 1992, as part of a national study commissioned by the American Association of Retired Persons (AARP, 1992). This study included the first working definition of AL: “a group residential setting not licensed as a nursing facility that provides or arranges personal care to meet functional requirements and routine nursing services” (Wilson, 2007, p. 14). Often, AL facilities are lumped with, or put under the grouping of, residential care facilities (RCF). In its *Residential Care and Assisted Living Compendium*, the U.S. Department of Health and Human Services (DHHS) uses “residential care setting” or “residential care facility” for all kinds of group residential

care settings in order to cover the continuum between home care and nursing homes. According to the DHHS, assisted living represents a “unique model of residential care that differs significantly from traditional types of residential care such as board and care” (Mollica, Sims-Kastelein, & O’Keeffe, 2007, pp. 1-1). A look at even the small sample of studies examined for this review shows a range of types of “assisted living” settings. Ball et al.’s (2004) study of aging in AL was conducted in Georgia, where “ALFs are termed ‘personal care homes’ and are defined broadly in statute to include a wide range of facilities with no limitations on size and only the specification that residents be at least 18 years old.” The two studies by Cartwright and colleagues (Cartwright & Kayser-Jones, 2003; Cartwright et al., 2006) were conducted in Oregon, which specifically requires AL units to be private, of a minimum size, and to contain a kitchenette and wheelchair-accessible bathroom with shower. In Oregon, the requirement for these features distinguishes AL from residential care (Oregon Consumer Guide: Assisted Living and Residential Care Facilities, 2005). An article by Dixon et al. (2002) offers no definition or explicit location for their study and uses the terms “assisted living facility,” “assisted living community,” and “assisted living centers” interchangeably without defining the setting further.

Munn & Zimmerman (2006) discuss residential care/assisted living (RC/AL) as part of the Collaborative Studies of Long-Term Care, a multi-state, longitudinal study. This study defined RC/AL “broadly as facilities or discrete portions of facilities licensed by the state at a non-nursing home level of care, which provide room, board, 24-hour oversight, and assistance with activities of daily living” (Zimmerman et al., 2003, p. 108).

They further distinguish between three types of RC/AL: facilities with fewer than 16 beds, facilities with 16 or more beds that are traditional board-and-care type facilities, and “new-model” facilities, defined as follows: “16 or more beds; built after January 1, 1987; [with at least one of the following additional characteristics]: (1) at least two different private pay monthly rates, depending on resident need; (2) 20% or more of the resident population requiring assistance in transfer; (3) 25% or more of the resident population who are incontinent daily; or (4) either an RN or an LPN on duty at all times” (Zimmerman et al., 2003 p. 108).

The lack of uniform definition makes it difficult to formulate comparisons across studies that may be conducted in facilities that differ in significant ways even if all are called “assisted living.” Nonetheless, there seems to be some consensus on some of the characteristics: a residential setting within a social model with limited healthcare services.

Aging in Place in Assisted Living

Initially, assisted living was envisioned as a setting that would accommodate individuals’ changing abilities and allow them to stay in the setting for as long as they desired, a situation commonly called “aging in place.” Aging in place was to be reflected in policies that did not routinely require residents to move out of their assisted living home, either to another setting or to another level of care in the same setting. Instead, all moves within and out of a facility would be voluntary. To facilitate this idea, the vision of assisted living included variable service capacity, incorporating a wide range of services that would be individualized to the residents’ needs and preferences. These services

include medication administration, dementia care, incontinence management, and hands-on assistance with all activities of daily living (Wilson, 2007). However, as older residents present with more complex care issues, are more functionally impaired, and are more dependent for care, the ability of AL to meet the needs of aging residents has been called into question. Furthermore, despite the original philosophy of accommodating changing needs, not all facilities allow hospice services for dying residents. One study found that 65% of AL facilities allowed hospice services (Ball et al., 2004). Some facilities prefer to discharge residents requiring end-of-life care (Dobbs, Hanson, Zimmerman, Williams, & Munn, 2006).

This review found only one study that specifically examined the ability of AL residents to age in place (Ball et al., 2004). Utilizing interviews, participant observation, and document review, data were collected on five AL facilities in Georgia. Each site was studied for a year, for a total of 1,436 hours of observation over the course of 457 visits. A major finding from this study was the relationship between successfully aging in place in AL and how well the resident and facility were able to manage the resident's decline. Aging in place seemed to depend not only on resident factors (e.g., health, function, and cognitive status, family support, and financial resources), and facility factors (e.g., size, ownership, admission and retention policies, staffing levels, services offered), but also on the ability to manage an acceptable level of risk for the resident and family. Discharge was often the result of changes in cognitive function and the development of unmanageable behavior symptoms. Family support was perceived as key to residents being able to stay in their AL home, although relationships with providers and other

residents were also contributory (Ball et al., 2004). The importance of family support in AL facilities to maintain placement in the AL facility has been replicated in other studies (Gaugler & Kane, 2007; Port et al., 2005).

While aging in place is desired by many residents and families (Ball et al., 2004; Cartwright & Kayser-Jones, 2003), Ball et al. (2004) also caution that it is not always the most appropriate choice, nor does it always have good outcomes. Staying in an AL means that a resident does not experience the stress of relocation or the loss of important relationships, but staying can lead to physical and social neglect because of staffing ratios and skill levels. In addition, the financial burden increases as residents require more extensive (and therefore more expensive) care packages. The decision to stay as a resident's needs increase has an impact beyond those that directly affect the individual resident. Increased needs place increased demands and stress on paid care providers and can influence the environment of the facility for other residents (Ball et al., 2004). The study by Ball et al. provided major contributions to understanding the phenomenon of aging in place, particularly in terms of "fit," managing risk and the impact of the relationships that develop within the AL setting on maintaining a resident within an AL facility as their care needs increase. While the Ball study did not specifically focus on end of life in AL, the trajectory and context of decline can be instructive when trying to understand the implications of end of life in AL, as many of the concerns (such as staffing levels and training, managing increasing needs, and balancing the needs of frail and more independent residents) are the same.

Demographics of Assisted Living

Between 1990 and 2002, there was a reported growth of 57% in residential care/assisted living facilities. Only seven states reported declines in facilities during this time period, whereas 12 reported growth rates of over 200% (Harrington, Chapman, Miller, Miller, & Newcomer, 2004). The average AL resident is aged 85, female, white, and widowed (*Statistics on Family Caregivers and Family Caregiving*, 2002). Data regarding resident income is difficult to identify in surveys of assisted living. One survey, conducted for the Assisted Living Federation of America indicated that, in 1997, the average income of AL residents was \$30,831 and their average net worth was \$153,000 (Marsden, 2005)¹

Despite being conceptualized as a housing option for individuals in stable health and not requiring 24-hour nursing care (Dixon et al., 2002), research indicates that AL residents are generally older and more functionally impaired than depicted earlier (Ditmar, 1989 as cited in Ball et al., 2004). Approximately two-thirds of AL residents need assistance with one activity of daily living (ADL), and approximately 26% are dependent in three or more ADLs (Mitty, 2004). Residents most often require help with bathing (68%), followed by dressing (47%), and toileting (34%), while 25% require help with transferring and 22% require help with eating (National Family Caregivers Association, 2002). The most common chronic illnesses are heart disease (28%), osteoporosis (16%), and diabetes (13%) (Marsden, 2005). Cognitive impairment is common: one study, using professionals trained in dementia evaluation and assessment,

¹ The difference between this average income rate and the average cost for an AL room cited in Chapter 1 can be explained by the ten-year difference in the two statistics.

found that 67.7% of its participants had “clinically significant cognitive dysfunction” (Rosenblatt, et al., 2004 p. 1266). This same study found that impairment is often unrecognized by the people closest to the AL residents: 22% of paid caregivers and 14% of families failed to identify study participants with dementia as having cognitive impairment (Rosenblatt et al., 2004). These results are slightly higher than other studies, which report cognitive impairment rates between 53% and 58% (Gaugler & Kane, 2007).

The overall proportion of U.S. deaths that occur in long-term care is 23%, a number that is expected to increase to 40% by 2040 (Munn & Zimmerman, 2006). Within AL facilities, the annual death rate is estimated to be approximately 30% (National Center for Assisted Living, 2006). This combination of increasing age, frailty, and mortality suggests that AL facilities will play an ever-increasing role in end-of-life care.

End-of-Life Care in Assisted Living

Information about end of life in assisted living is very limited. While we know that people die in AL, the way in which the experience unfolds for the resident, staff, and family is relatively unknown (Cartwright & Kayser-Jones, 2003). Studies cite an annual death rate of between 14% and 28% (Cartwright et al., 2006; Dobbs et al., 2006), but it is not clear how many of these individuals are actually transferred to a hospital or other higher care level before they die. We do not know how many AL facility residents receive end-of-life care compared to those who die but were never identified as approaching the end of their life, and therefore did not receive terminal care per se.

While the desire to make assisted living a final home is frequently stated by residents and families (Ball et al., 2004; Cartwright & Kayser-Jones, 2003; Cartwright et

al., 2006; Dixon et al., 2002; Munn & Zimmerman, 2006), it is clear that there are many challenges to providing appropriate end-of-life care. The often rapidly changing nature of terminal disease presents different demands than the typical requirements of AL residents who may need assistance with ADLs, health status monitoring, and oversight (Dixon et al., 2002). The complexity of end-of-life care is often further exacerbated by the need to manage a resident's chronic conditions as well as their cognitive and functional limitations (Cartwright & Kayser-Jones, 2003). Furthermore, residents may be bed-bound by the time of death and may be suffering from pain, dyspnea, nausea, or confusion, and thus require a high level of symptom management in environments where the presence of licensed nursing staff is often extremely limited.

As noted in Tables A1 and A2, other challenges related to end-of-life care in assisted living include staffing levels, the staff's lack of knowledge of or experience with providing terminal care, and the increased complexity of communication and coordination of care. Nonetheless, many family members express their satisfaction with the outcome when their loved one is able to die in their AL home, feeling that their symptoms were well managed and that the caring, attentive nature of the care provided by staff who (often) knew the resident well made staying in the AL facility, rather than moving to a facility with a higher level of care, worthwhile (Cartwright & Kayser-Jones, 2003; Cartwright et al., 2006; Dixon et al., 2002; Munn & Zimmerman, 2006)

There is a great deal of confusion on the part of families and outside providers regarding the level of care that AL facilities can, and are willing, to provide. This is further compounded by a lack of clarity on the part of AL facilities as to the extent and

limit of their capacity, and their expectations of hospice and family members (Dixon et al., 2002).

Hospice use in assisted living still appears to be limited, and while the level of use appears to be much below that found among nursing homes, use is increasing (Dobbs et al., 2006). The specific concerns of hospice providers working in AL facilities relate at least in part to the limited experience that hospice agencies have with the setting, as well as confusion regarding roles and responsibilities among AL staff, hospice staff, and family caregivers. Hospice personnel cite many of the same challenges that families note, such as staffing levels and consistency, level of monitoring, communication, unrealistic expectations of the capabilities and role of hospice, and challenges with the physical setting and other logistics (Cartwright et al., 2006; Dixon et al., 2002). Despite the specific barriers and strains, hospice personnel generally see the need to try to meet the desire of AL residents to stay in their home and to adjust their care models to accommodate the setting (Dixon et al., 2002).

Family Caregivers in Long-Term Care and Assisted Living

There is clear evidence of continued family involvement and engagement in the lives of their relatives in both nursing homes and assisted living (Friedemann, Montgomery, Maiberger, & Smith, 1997; Gaugler & Kane, 2001; Perkinson, 1995; Ross, Carswell, & Dalziel, 2001; Sanderson & Meyers, 2004; Wright, 2000). Studies have shown that most assisted living residents have regular contact with their families. In a review of the literature by Gaugler and Kane (2007), the authors noted that most AL residents have family nearby who not only visit, but provide various levels of informal

care. What limited research exists has found that family caregiving is important for older residents in AL facilities, and that the monitoring of resident health and well-being by families of AL residents leads to clinical outcomes similar to that of NHs, despite the fact that NHs provide a higher level of professional care (Port et al., 2005).

The nursing home environment is a useful comparative model when examining involvement of family members of AL residents; however, it is important to keep in mind the differences between the two settings, particularly in terms of the level of burden for family caregivers. In at least one study, family caregivers of AL residents rated both their involvement and burden as higher than family members of NH residents (Port et al., 2005).

Family Caregiving Roles in Nursing Homes and Assisted Living

As can be noted in tables A3 and A4, family caregivers fulfill many roles to meet the needs of their relatives residing in nursing homes and assisted living. Friedemann et al. (1997) and Sanderson and Meyers (2004) describe occasional instances of family caregivers being involved with personal, hands-on care such as help with bathing, eating, or dressing. In studies that compare AL and NHs, family caregivers of AL residents provided more direct and instrumental care than family members of NH residents (Gaugler & Kane, 2001; Port et al., 2005). One AL study described family caregivers who visited daily and aided the resident by helping them get up or get ready for bed, helping with meals, or taking them to regular appointments such as thrice-weekly dialysis (Ball et al., 2004).

Some of the caregiving activities that family members engage in with their AL resident include companionship (Friedemann et al., 1997; Ross et al., 2001; Sanderson & Meyers, 2004; Wright, 2000); financial management (Port et al., 2005; Wright, 2000); advocacy (Friedemann et al., 1997; Ross et al., 2001); organizing care (Friedemann et al., 1997; Ross et al., 2001); medication administration (Sanderson & Meyers, 2004); and preservation of a sense of self (Friedemann et al., 1997). Families monitor staff and the quality of care they provide (Gaugler & Kane, 2007; Wright, 2000), as well as the general well-being of the resident (Port et al., 2005).

In a longitudinal study by Gaugler and Kane (2001), it was observed that AL residents received more types of instrumental assistance from families than NH residents, and that this assistance remained constant over time. While there are likely many factors that explain the difference in care provided by family members for AL and NH residents, one major difference is the fee structure. Assisted living facilities offer a range of service packages, the cost increasing with the level and amount of care provided by the facility. The degree of family caregiving provided in AL may have a direct relationship to financial status and an attempt to control costs.

Expectations of Family Caregivers in Nursing Homes and Assisted Living

One of the issues in the AL setting, particularly as compared to nursing homes, is the lack of clear expectations regarding whose responsibility it is to provide what care. This ambiguity can make the line between formal and informal caregiving unclear. It can be an impetus for a higher level of monitoring and advocacy and may create a higher level of stress and other health problems in family members after they have placed a

relative in an assisted living facility (Sanderson & Meyers, 2004). Family caregivers do not necessarily expect to be heavily involved with care, nor are they necessarily prepared for the intensity of the experience (Ross et al., 2001).

Staff attitudes and expectations regarding family caregivers tend to differ between nursing homes and assisted living facilities. While some NH facilities actively encourage the involvement of family members (Friedemann et al., 1997), the nature of that involvement may be more prescribed than in AL, since some tasks (such as personal care or medication management) are considered the clear responsibility of the nursing home and NH staff. In AL facilities, boundaries are more ambiguous, and expectations, explicit or implicit, are more open to interpretation (Port et al., 2005). Additionally, issues of control—of both the environment and of caregiving responsibilities—are much more likely to occur in the NH environment, where family-provided care is generally (and generally expected to be) indirect and focused on the emotional well-being of the resident (Ross et al., 2001). In the NH setting, a higher level of involvement by family caregivers is more likely to be seen as “interference” (Port et al., 2005).

Gaps and Limitations

In reviewing research on family caregiving and assisted living, the limitations of extant studies become apparent. Many studies look only at frequency of contact. The focus is on very concrete tasks (such as assistance with ADLs and IADLs) or on other categories created by the researchers. Although monitoring and advocacy appear to be important functions of family caregiving (Gaugler & Kane, 2007; Port et al., 2005; Wright, 2000), these activities are neither described nor discussed in any depth. Nor is

there much evidence of how family caregiving influences psychosocial or functional outcomes, or the ability to age in place (Gaugler, 2005).

There is little discussion in the literature reviewed of the effect that care provision has on family caregivers. Stress and burden are occasionally mentioned, but issues related to role transition, relationship continuity, emotional distress, or what it means to family caregivers to be caring for an AL resident are absent. Without a better understanding of *what* family caregivers do, *why* they are or aren't willing to do these things, and the *impact* of these activities on family caregivers, it is difficult for healthcare providers to know how best to support family caregivers in their efforts, or to find out what family members are willing to do.

Family Caregivers of Long-Term Care and Assisted

Living Residents at End of Life

Family Caregiving Roles for NH and AL Residents at End of Life

Five articles containing information related to family caregiving of AL residents at end of life were located, retrieved, and reviewed (see tables A1 and A2). Four of these studies focused on the perceived end-of-life experience for the dying resident (Cartwright & Kayser-Jones, 2003; Cartwright et al., 2006; Munn & Zimmerman, 2006; Sloane et al., 2003); two focused on the process of providing end-of-life care (Dixon et al., 2002; Munn & Zimmerman, 2006); and two examined family satisfaction (Cartwright et al., 2006; Sloane et al., 2003). Discussion of family caregiver roles and activities was limited. Cartwright and Kayser-Jones (2003) posited that family involvement may be critical to end-of-life care in AL facilities, and Munn & Zimmerman (2006) described categories of

activities such as social support, monitoring, advocacy, providing direct care and a desire to be present at death. The impact on family caregivers of a relative receiving end-of-life care in an AL facility was explored in one study (Cartwright & Kayser-Jones, 2003). In this study, responses related to the expectations to provide care.

In the articles that focused on end-of-life care in nursing homes (see tables A5 and A6), three included family members as participants (Baer & Hanson, 2000; Bosek, Lowry, Lindeman, Burck, & Gwyther, 2003; Goodridge, Bond, Cameron, & McKean, 2005). None of these manuscripts directly discussed what family members do for their dying relatives, although one mentioned that some family members expressed a desire to be present or help with care of their dying relative (Goodridge et al., 2005). The focus in all these studies was on the quality of end-of-life care and/or the quality of the dying process. One study, which did not include family members as participants, was particularly critical regarding the absence of family and what facility staffs saw as the “interference” of family when they made an eleventh hour appearance (Hanson & Henderson, 2000). In the study by Travis and colleagues (2002), all data were collected via chart review and examined the obstacles to good end-of-life care in NHs. In these studies, the family member role appears to be limited to that of decision-maker.

Barriers and Facilitators for Family Caregivers of NH and AL Residents at End of Life

From the studies available, it appears that family caregiving at end-of-life care in nursing homes and assisted living facilities have many parallels. Family caregivers in both settings expressed concerns about symptom management (Baer & Hanson, 2000;

Bosek et al., 2003; Hanson & Henderson, 2000); communication and coordination of care (Goodridge et al., 2005; Travis et al., 2002); late recognition of dying and referral to hospice (Baer & Hanson, 2000; Dixon et al., 2002; Munn & Zimmerman, 2006; Travis et al., 2002); and lack of local family (Dixon et al., 2002; Hanson & Henderson, 2000).

Challenges that appear to be unique to AL and family caregivers supporting their relatives in AL facilities reflect the underlying differences in the nature of the two settings. Staffing levels and clinical knowledge (particularly regarding end-of-life care) were cited as issues in AL (Cartwright & Kayser-Jones, 2003; Cartwright et al., 2006, Dixon, et al., 2002), as well as family and residents not understanding about levels of care and the attendant costs (Dixon et al., 2002). Other issues cited related to expectations regarding roles and responsibility and accountability for care (Cartwright & Kayser-Jones, 2003; Dixon et al., 2002).

In both settings, major facilitators of care and family involvement were the relationships of staff with residents and the caring and support that staff showed to both residents and families (Cartwright & Kayser-Jones, 2003; Dixon et al., 2002), as well as the involvement of hospice (Baer & Hanson, 2000; Cartwright et al., 2006; Munn & Zimmerman, 2006). The most striking difference was that AL facilities were seen as “home” and therefore a desirable place to die (Cartwright & Kayser-Jones, 2003).

Gaps and Limitations

More information is needed regarding how family caregivers interact with others involved with providing end-of-life care for the AL resident; the roles the family caregivers fill in caring for their dying relatives; the type of support (education, physical,

financial emotional) they need while providing end-of-life care; and the impact that caregiving has on other facets of the family caregiver's life.

If family caregivers are not prepared for the level of commitment necessary to ensure the health and well-being of their relative in an AL facility, it is a matter of concern how those caregivers can, and will, respond when faced with the additional challenges of caring for someone at end of life. Knowing how families respond to the added demands of end-of-life care and knowing their challenges and needs can shape policy and practice in assisted living. For example, a facility may require a specific level of family involvement in end-of-life care as a condition for the AL resident staying in the facility until death, or change their service package (and attendant cost) to specifically cover end-of-life care. We do not know when and how families and residents receive information related to failing health and end of life, or what difference appropriate preparation for end-of-life care in assisted living may provide.

Summary of the Review of Literature

While assisted living as a research setting is relatively new, the body of knowledge is growing. It is clear that while some parallels can be made with other long-term care settings, there are enough unique aspects to the AL environment that it warrants study as a separate phenomenon. It is also clear that any research in the AL setting needs to explicitly define "assisted living," as the range of settings so labeled makes any generalization difficult without an explicit understanding of the research context.

It is apparent that family members are involved with assisted living residents, and that their involvement may have a positive impact on the resident's ability to stay in their

AL home. There is evidence that family caregiving occurs throughout the course of a resident's tenure, up to and including their death in the AL setting. There are some limited reports regarding the types of activities that family members engage in with their AL residents, as well as some of family members' motivating factors, but data regarding family caregiver involvement in end-of-life activities is extremely limited. There are also no data regarding how family members perceive themselves within the context of this care; in other words, what role they see themselves performing. While there are some data regarding families' lack of understanding of the care limits of AL, there appear to be no data regarding their expectations for themselves, the facility, or any outside care providers, particularly at end of life. There is little or no information, particularly from the family member's perspective, about the nature of interactions between family members and AL staff, or between family members and outside care providers (such as hospice staff).

While there has been passing mention of negative sequelae from family members providing end-of-life care, there is scant evidence of the impact, either positive or negative, of this caregiving on the family members themselves, either while engaged in care or after the resident's death. Furthermore, there is no information regarding the challenges and issues that family members face when helping to care for their AL resident who is approaching the end of their life. Therefore, this study explored the unique needs of family caregivers involved in end-of-life care for aging family members in assisted living facilities.

Chapter 3: Research Design and Method

Overview: Design

This exploratory study used a qualitative descriptive design (Sandelowski 2000) to explore and describe the experiences of family caregivers of elder assisted living (AL) residents enrolled in hospice. Interview and observational data were collected from family members who self-identified as “very involved” in the care of the resident. The goals of the study were the following:

1. Describe the various roles that family caregivers play in end-of-life care for older adults enrolled in hospice who live in assisted living facilities.
2. Describe the expectations that family caregivers have for themselves, the assisted living facility, and hospice personnel involved in providing end-of-life care for older adults enrolled in hospice.

Sample

In this study, purposive sampling was used to identify family caregivers of AL residents enrolled in hospice: specifically, the individuals identified as most involved with end-of-life care for AL residents over the age of 65 who had been enrolled in hospice for at least one week. In those cases where it appeared that other family members were involved with care, permission was requested to contact them as well.

Potential participants were recruited through three hospice agencies located in a major metropolitan area of the Pacific Northwest. One of the agencies was a for-profit organization with ties to a chain of AL facilities. The other two were not-for-profit agencies and were associated with larger health-care systems. I visited each hospice

agency and provided an overview of the study and recruitment brochures to hospice staff, including RNs, social workers, and chaplains. These hospice staff were asked to identify individuals who met the criteria for inclusion and ask them if they were willing to be contacted by me as the principal investigator (PI). Several staff from each site agreed to assist with recruitment.

The hospice staff made a total of ten referrals of individuals who were eligible and interested in participating in the study. These referrals were then contacted, provided with more information and an opportunity to ask questions. Three individuals declined to participate after receiving the phone call from the investigator. None offered specific reasons for their refusal. Seven individuals agreed to be in the study. All participants were referred from two of the agencies, a for-profit agency and one of the not-for-profit agencies. Three participants identified other family members who were also involved in caregiving. These participants were asked to discuss the study with other family members. Two of the participants agreed to do so and another three participants were recruited in this manner. The final sample consisted of 10 family caregivers (FCG). All the FCGs were white, eight were female, and two were male. The FCGs ranged in age from 48 to 85 years old, with a mean age of 64.8. Two FCGs were wives, two were sons, and six were daughters, including one stepdaughter and one daughter-in-law. See Table 1 for demographic details.

Table 1

Family Caregiver Demographics

FCG (CR)	Age	Gender	Marital Status	Relationship to CR	Work Status	Educa-tion	SES^a
Lydia (Donna)	85	Female	Married	Daughter	Retired	HS grad	\$35–59K (3) ^b
Jay (Doris)	83	Male	Married	Son	Retired	5 years college	\$100K (4)
Diane (Sally)	62	Female	Widowed	Daughter	Working FT	HS grad	\$35–59K (2)
Lisa (Edith)	63	Female	Married	Daughter	Retired	2 years college	\$100K (4)
Kay (Ann)	59	Female	Married	Daughter	Working FT	1 year college	\$20–39K (3)
Tom (Ann)	55	Male	Married	Son	Working FT	HS grad	(3)
Debbie (Ann)	55	Female	Married	Daughter-in-law	Working PT	HS grad	(3)
Sunny (Keith)	68	Female	Married	Wife	Retired	4 years college	\$60–99K (4)
Ileana (Sasha)	70	Female	Married	Wife	Retired	Master's degree	(2)
Raisa (Sasha)	48	Female	Separated	Step-daughter	Working FT	Master's degree	\$20–39K (2–3)

Note. All names are pseudonyms. FCG = family caregiver, CR = care recipient.

^a Participants were asked to describe their annual earnings as being one of the following: \$0–\$9,999; \$10,000–\$19,999; \$20,000–\$34,999; \$35,000–\$59,999; \$60,000–\$99,999; \$100,000+. Not all participants provided income categories.

^b Participants were asked to describe their ability to get along on their income as: (1) I can't make ends meet; (2) I have just enough, no more; (3) I have enough with a little extra sometimes; (4) I always have money left over.

The FCGs were providing care to seven care recipients (CRs). All the CRs were white, five were female, and two were male. All of the CRs experienced some kind of life-limiting chronic illness. The CRs' age range was 68 to 105, with a mean age of 88.3. Length of stay in assisted living (at the end of involvement with the study) ranged from three months to five years, with a mean of 26 months. Hospice length of stay (at the end of involvement with the study) ranged from two to twelve months, with a mean of six months. See Table 2 for demographic and other details.

Table 2

Care Recipient Demographics

Name	Age	Gender	Terminal Diagnosis	LOS–AL Facility	LOS–Hospice
Donna ^a	105	Female	Breast CA (end-stage dementia)	5 years	1 year
Doris	102	Female	Cardiac	7 months–9 months	3 weeks–2 months
Sally ^a	82	Female	Heart failure	3 years–3.5 years	6 weeks–4.5 months
Edith	85	Female	HF/Pulmonary fibrosis	1 year–1 year 4 months	4 months–8 months
Ann ^a	88	Female	Heart failure	3.5 years–3 years 8 months	4 months–7 months
Keith	68	Male	Cardiac: 8 years post stroke/heart failure	3 days–6 months	1 week–6 months
Sasha ^a	88	Male	Dementia	5 weeks–3 months	2 weeks–2 months

Note. LOS = Length of Stay. When the assisted living or hospice length of stay is stated as a range, the first number refers to the care recipient's status when they joined the study, the second number refers to when the CR died or contact with the participant ended.

^a Indicates the care recipient died during the study.

Procedures

Data Collection

Data were collected in face-to-face interviews in the location of the participants' choosing and during observations of the FCG and CR in the AL facility. A total of thirteen interviews were conducted, nine initial interviews and four follow-up interviews. All but one interview was conducted in the home of the FCG. One was conducted at the FCG's work place. Two participants, a husband and wife, were interviewed together. Initial interviews lasted from 50 minutes to 2.5 hours. Follow-up interviews, conducted with four participants, lasted from 20 minutes to 3 hours. All interviews were audio recorded. Four participants and care receivers agreed to being observed. A total of fourteen observations were conducted. The number of observations per the four participants ranged from two to six. Observations lasted from 45 minutes to 2 hours. The observations occurred over a period of two to six weeks. Field notes were taken during observations, and supplemented with audio-recorded field notes made immediately upon leaving the observation site. Field notes described observations, initial impressions and verbal interactions between the participant, the care recipient, and/or myself. In addition to interviews and observations, telephone contact was maintained with six of the participants. Phone calls were logged and the conversation described. Participants remained active in the study for a range of one week to six months.

Instruments

A semi-structured interview guide was used during the interviews (See Appendix B). The interview guide was pilot tested with individuals who have had similar

experiences (caring for a family member at end of life who lives/lived in an assisted living facility), but were not eligible for the study. One of the individuals was also a nurse practitioner, doctorally prepared nurse researcher, and content expert in end-of-life care. The pilot testing checked the usability and clarity of the interview guide and allowed for practice asking the interview questions. Adjustments were made following feedback from the pilot interview participants. Study data were not collected from participants in the pilot phase of this study. During the course of data collection and analysis, the interview guide was further modified with additional questions and modifications of extant questions. Issues raised in prior interviews or initial analysis were incorporated into interviews. In addition, demographic data on both the FCG and CR were collected.

An observation guide was also developed and used as a general guide during the observation sessions (See Appendix B). Observations focused on the participant's interactions with the AL resident and others who were involved with the AL resident. In addition, factors related to the social, physical, and organizational environments were noted.

Data collection and analysis were concurrent, with analysis informing and influencing further data collection. Shortly after completing each interview, recordings were listened to again to gain an overall sense of the participant's story. Recordings were then transcribed verbatim and reviewed for accuracy. In order to ensure confidentiality, identifying data were omitted from the transcripts and each participant and CR was given a pseudonym. Written field notes were typed up, taking fragments written at the time and

adding details. Recorded field notes were transcribed verbatim, reviewed for accuracy, and combined with the written field notes.

Data Analysis

To begin the analysis of the data, extensive summaries were written for the first three interviews. Analyses of these data were begun before data collection was complete. The analysis was a complex, iterative process; however, it can be separated into distinct, yet overlapping, phases.

Phase one: coding. Completed and corrected transcripts of interviews, observations, and phone conversations were imported into QSR International's NVivo 8 qualitative data analysis software to manage and assist in the analysis of these data. After being imported, transcripts were read carefully for descriptions of the participants' experiences and perceptions regarding caregiver activities and expectations; participant behaviors and interactions; and the key concepts and themes that emerged. Salient passages were coded in a "free codes" or open coding process at first with no attempt to categorize the codes. Codes were then defined. Codes continued to be created throughout the process of coding interviews and observations. Older interviews and field notes were reread and data that could be ascribed to the new codes were tagged.

As the process of reading and coding interviews progressed, codes were arranged in hierarchical "trees." These trees allowed for similar concepts to be grouped together. Some trees were organized to reflect the specific aims of the study. Other trees arose from the process of constant comparative analysis and involved analyzing the data to uncover patterns and commonalities as well as variations on the patterns both within and

across data sets. Comparisons were made within interviews and across interviews as well as across observations of the same participant over time. Comparisons were made across codes and categories, allowing for new dimensions, variations, and relationships to be discovered, as well as uncovering other factors present and the conditions under which particular patterns appeared. Throughout this process some codes were collapsed into each other, and some codes were split into different trees as language and terms were examined and reexamined for the most appropriate conceptual fit.

Throughout the analysis process, theoretical memos were recorded to provide a written record of the development of analysis and attendant thoughts in the course of the study. Theoretical memos explored the first impressions, emerging patterns, questions raised, and emerging concepts regarding family caregivers of assisted living residents enrolled in hospice. Methodological memos were also written regarding recruiting, the interview guide, the interviewing and observation process, the coding and analyzing process, and decisions made regarding the study.

Phase two: initial analysis. The initial comprehensive analysis of the data focused on data that related to the specific aims of the study. A first analysis was performed on family caregiver roles. Codes under the “Caregiver role” major heading were examined for patterns and separated into four categories related to what the family caregiver did *for* the CR, *with* the CR, *to* the CR and in *orchestrating care* for the CR. Queries were then run collating all the data related to each of the four categories. Within-case analysis resulted in summaries of FCG activities divided by categories, as well as a description of how these activities changed over time. Following within-case summaries,

across-case analysis revealed themes and patterns regarding activities FCGs engage in, FCG responses to activities, and factors affecting what FCGs do. From this analysis, initial concepts related to family caregiving activities were advanced.

Analysis of FCG expectations was also an iterative and evolving process, as was the process of defining and delineating the concept of “expectations.” Queries were run of relevant codes for expectations of AL facility, expectations of hospice, and expectations of self. Within-case data were examined for each subset of expectations and summarized. Across-case analysis was performed to find commonalities and differences in expectations, followed by an examination of themes, patterns, variances, and responses. Theoretical memos were then generated proposing reasons for differences across caregiving situations.

In order to capture the time element, data were organized by trajectory. Summaries were created that described the illness trajectory of each CR, the changes that occurred across time for the FCG, and how expectations changed. Summary descriptions of the tradeoffs that FCG were able to accept when expectations were not met were also created. In-depth analysis of the data was also performed on the emerging concepts of hospice as “gap filler” and financial concerns.

After initial analysis and organization of the data based on the study’s original aims, the results were perceived as not fully capturing the richness and depth of participants’ experiences or perceptions. In the continued effort to uncover the essence of the caregiving experience these data described, it was determined that the most salient

aspect of the caregiver activities was how they change over time and the meaning of those changes.

Building on the analysis already performed on the CR trajectory, another approach to examining the data was executed. The initial step was to capture the temporal aspect of the caregiving experience in an effort to uncover what might influence changes in caregiving over time.

Phase three: graphing trajectories and generating factors. Through analysis of data, varying levels of caregiving involvement were uncovered. In order to visualize this, the FCG's involvement levels were graphed (See Appendix C). Analyzing the graphed caregiving intensity raised questions regarding what factors might influence different patterns of involvement among the FCGs. Through further data immersion, it was discerned that a set of seven factors should be further explored to examine potential interaction with FCG involvement.

Phase four: coding and analyzing factors. The data were recoded in NVivo using these factors. Reports were run for each of the factors. The report was then exported to a Word document. The Word document was analyzed for themes related to the factor and labeled or "tagged" as such using track changes. The phrases used to tag the relevant pieces of data were then collected and sorted and grouped into categories. Using the sorted tags, the original data bits were sorted in the same manner. Using the combination of the sorted/grouped tags and the relevant data bits, theoretical memos were written for each of the factors. This material served as the basis for the final results write-up and model.

Verification of Analysis

Any research must be able to present its findings in such a way as it can demonstrate rigor and validity. I used the framework of Lincoln and Guba (1985), who framed this requirement in terms of *trustworthiness*, which they further defined as the qualities of *credibility*, *dependability*, *conformability*, and *transferability*.

Credibility examines the believability of the findings. Credibility of the findings is supported by prolonged engagement, persistent observation, and triangulation (Lincoln & Guba, 1985). Prolonged engagement and persistent observation were achieved by repeated observations of participants over time and follow-up interviews. The observations augmented the data collected from the interviews, led to further lines of questioning that were not otherwise apparent, and served to illuminate concepts not apparent prior. Follow-up interviews allowed for the participants to reflect back on their experience, and in the cases where the CR had died, allowed for responses that were less influenced by the stress of managing the unfolding situation. Triangulation was achieved by using two data collection methods, interviews and observation. Peer debriefing occurred through the process of committee review and oversight as well as bringing data and the evolving data analysis for discussion and comment to a doctoral student dissertation seminar. This seminar allowed for feedback from a larger pool of individuals who brought a fresh perspective to the analysis. Further feedback was solicited in the form of responses to preliminary results reported in poster and podium presentations given at international conferences of gerontologists and hospice and palliative care providers and researchers.

Dependability refers to whether the findings provide an accurate portrayal of the experience through accurate and acceptable analytic methods (Lincoln & Guba, 1985). Dependability is often established through an external audit and a dense description of methods (Lincoln & Guba, 1985). The data collection and analysis processes were monitored and audited by my committee members, Drs. Harvath, Cartwright, and Miller who have complementary backgrounds in family caregiving, end of life, assisted living, and qualitative descriptive analysis. The committee oversaw and guided the data collection and analysis process, regularly challenging my thinking and analysis to ensure the analysis remained grounded in the data and within the scope of the study. The dissertation committee examined transcripts, coded data, and theoretical memos in order to provide confirmation of the accuracy of interpretation throughout the data collection and analysis phase. I also received feedback and critique of my data and analysis from my student colleagues in the course *Dissertation Seminar*.

Confirmability deals with the extent to which the findings of a study are shaped by the respondents and not by researcher bias, motivation, or interest (Lincoln & Guba, 1985). An *audit trail* was established through various documents describing the steps of the project from the start of the research study to the development and reporting of findings.

Recordings and notes were made of the key discussions and decisions related to analysis and the further direction of the study. Weekly meetings with Dr. Harvath as well as meetings with my committee helped me clarify my thinking and alerted me to places where assumptions or personal bias were moving analysis away from the data.

Transferability concerns the potential for the findings to be transferred to another setting, context, or population (Lincoln & Guba, 1985). Transferability can only be evaluated in the presence of *thick descriptions*, which provide rich detail, including contextual and methodological elements. Transferability is determined by the reader, who can evaluate whether the descriptions are clear and vivid enough to allow a true analysis of the applicability of the findings to another situation. To aid the reader in this process, the results describe rich detail regarding all relevant aspects of the study.

It is important to note that although the phases of analysis and verification are described linearly, this was an iterative process. The analysis involved repeatedly returning to the data to confirm that conclusions were not straying from the original material, and both creating and revising theoretical memos as more data informed the earlier ideas. My efforts were aimed at capturing and providing the reader access to the complexity of the experiences of these family caregivers providing end-of-life care for their family members residing in assisted living, without oversimplifying the process. The results of the analysis are presented in the next chapter.

Protection of Human Subjects

Every effort was made to protect the rights of participants in this low-risk, non-interventional study. A research proposal was submitted and approved by the Oregon Health and Science University Integrity Office Institutional Review Board.

Informed consent was obtained from all participants before the first interview. The consent form (see Appendix C) described the risks and benefits from participating in the study, the methods and goals of the study, and the participant's right to withdraw

from the study at any time. The form made explicit the methods used to protect confidentiality during the analysis of the data and reporting findings. These procedures included using pseudonyms to identify participants and other individuals who were observed, as well as affiliated organizations and agencies; keeping signed consents, audio recordings, and transcripts in a locked cabinet and transporting data in a locked bag. Identifying information was accessible only to the investigator. Names of individuals and institutions were removed from all transcripts, field notes, and memos to eliminate personally identifying information. Only the investigator, research assistants, and dissertation committee had access to the raw data.

Participants could have experienced some discomfort or distress during the interview or observation process. The risk of potential distress was clearly stated in the consent form, with the understanding that participants could withdraw from the study at any time without repercussion. One participant, after being interviewed and observed on two occasions, requested to withdraw from the study.

No observations occurred at the AL facility without the verbal assent of the AL resident. The investigator's presence and intent was made clear to the assisted living facility employees where observation occurred. The investigator identified herself whenever a new person entered the AL resident's apartment and clarified her role. Permission was always obtained to remain in the room while other personnel were present.

Chapter 4: Results

The purpose of this study was to explore the experiences of family caregivers (FCGs) of assisted living facility residents enrolled in hospice. The study examined family members' descriptions of their involvement in providing end-of-life care to relatives residing in assisted living (AL) facilities. The original aims of the study were the following:

1. Describe the various roles that family caregivers play in end-of-life care for older adults enrolled in hospice who live in assisted living facilities.
2. Describe the expectations that family caregivers have for themselves, the assisted living facility, and hospice personnel involved in providing end-of-life care for older adults enrolled in hospice.

As the study unfolded, however, these two aims did not seem to capture what was most salient for the family caregivers who participated in this study as they provided care for older relatives at the end of life. Particular themes arose repeatedly among the participants, including concerns about the care recipient (CR) not being able to stay in the AL residence and needing to be transferred to a nursing home setting; the need to attend closely to costs; and concerns about whether the money supporting the CR would be sufficient to meet the CR's needs over time. The concept of a common "overarching goal" framing the caregiving emerged from the realization that these concerns were the focus of the FCG's efforts. This overarching goal was to meet the changing needs of the CR so that they could die in the AL facility and avoid nursing home placement. In order to achieve this goal, the FCGs monitored the CR's changing needs, maintaining a

patchwork of care that wove together the AL and hospice services, involving extended family if possible or appropriate, and filling any remaining gaps themselves. The intensity of family caregiving changed over time as the CRs' needs changed, and in response to the perceived effectiveness of AL and hospice services. These discoveries will be the focus of this chapter.

Conceptual Model

A model was developed to describe the dynamic nature of, and the interactions between, the factors influencing FCG activity and intensity of caregiving. Given the FCG's overarching goal to maintain the AL placement until the CR's death, FCGs engage in a continuous process of monitoring the CR's needs and assessing how well those needs can be met through a combination of AL, hospice, and to a lesser degree, family involvement in care. The FCGs respond to any unmet CR needs by either managing the care provided by others or supplementing the care with direct care activities themselves. The intensity of involvement in care is mediated by the competing demands on the FCG and on the quality of his/her relationship with the CR. As the CR's needs change over time, so does the FCG involvement in care; the FCG either increases or decreases the intensity of their involvement depending on their appraisal of the CR's changing needs.

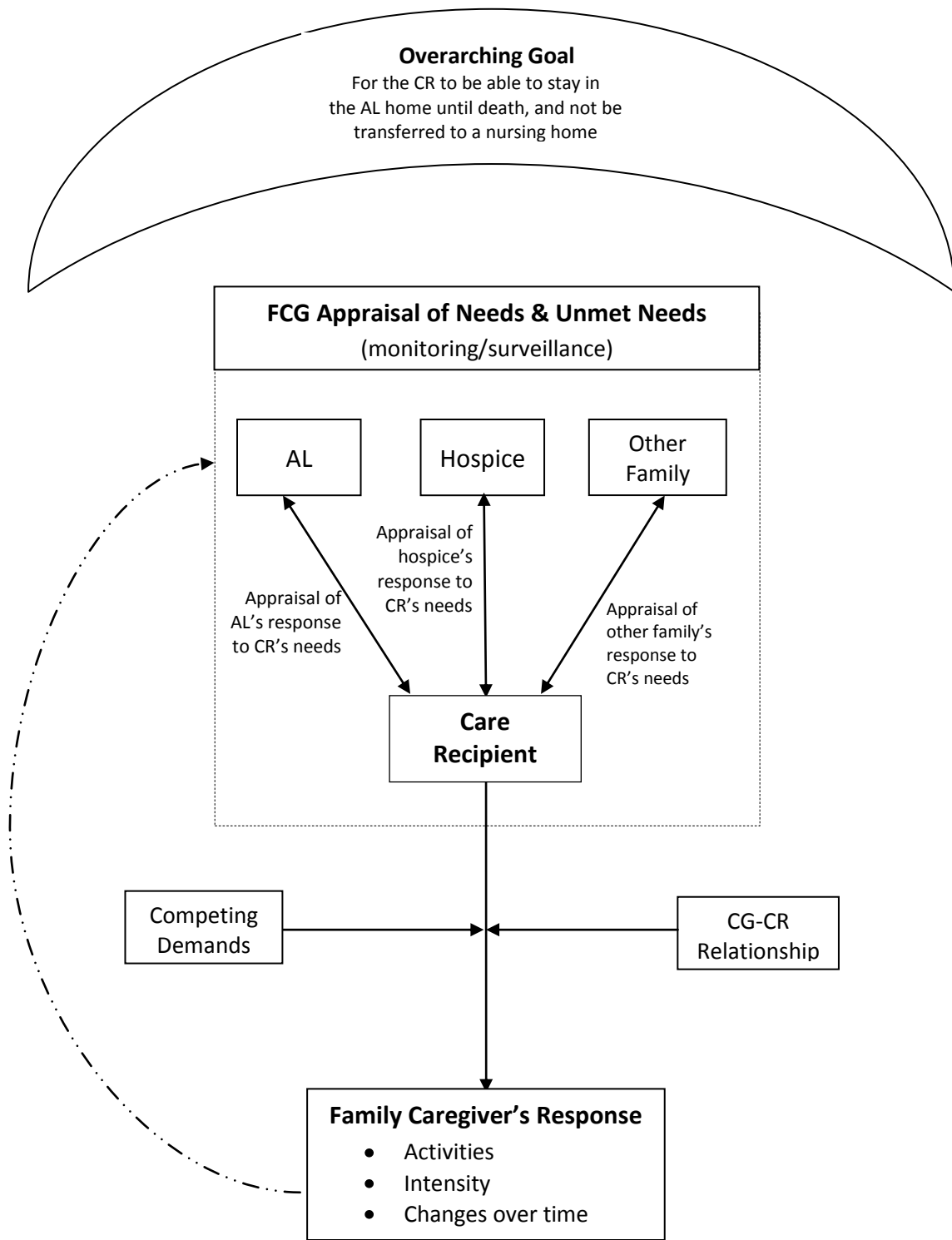


Figure 1 Conceptual Model

Overarching Goal

All of the family caregivers had a strong desire to avoid having their family member transferred out of their current assisted living home, although the reasons for resisting transfer varied. For participants whose family members had lived in the facility for an extended time, the issue was one of disruption and loss of a known and comfortable environment.

[The AL facility] is pretty doggone nice...she has her own little bedroom, they take good care of her, and I just don't want to have to move her again, for her sake. (Lydia¹, interview)

Most FCGs believed that, if the family member did have to move, it would be because their current setting could no longer support their needs. Almost universally, participants assumed that if the CR was not able to stay at the AL facility, moving to a nursing home was the only remaining option. Moving the CR was considered a less-than-satisfactory choice, with responses ranging from a willingness to concede that a move might be a necessary, though not desirable, outcome, to seeing it as something to be avoided at all costs.

Assisted living is one thing but, then, you know, the next step beyond that is a nursing home, and that – you know that's bad. (Lisa, interview)

Maintaining AL placement was often motivated by a desire to avoid moving the CR to a nursing home.

For some of the FCGs, there was an undercurrent of distress related to money, and finances and financial concerns were often mentioned. While income and financial security varied widely among the participants, financial issues absorbed a significant

¹ In order to protect the confidentiality of participants and the AL facilities, all references to subjects, agencies, AL facilities and other individuals are pseudonyms.

amount of energy for all of the FCGs.

Several FCGs voiced their fears regarding the ability of the CR to continue to bear the cost of the AL facility, and whether financial pressures might precipitate a move. The concerns led some FCGs to hope the CR died before the money ran out. Financial worries did not drive care decisions, but they created additional stress for some caregivers.

I'm worried about if we run out of money, what happens then? (Diane, interview #1)

Whether the fear of moving was a pressing concern or not, all participants discussed the impact financial issues had when decisions were made for the care recipients.

You don't think about every dollar, you have to think about every penny. You have to watch everything. (Ileana, observation #3)

The overarching goal influenced a FCG's caregiving activities and the intensity of the caregiving that they provided. Both the activities and their intensity were influenced by the FCG's assessment of the ability of the formal caregiving entities (AL and hospice) to meet the CR's needs, and by the FCG's assessment of what they might have to do themselves to fill any gaps in care. In other words, the FCGs hoped that balancing the perceived needs of the CR with support provided by the AL facility, hospice, and the FCG would make it possible for the CR to stay in their AL home until death. This involved an ongoing appraisal of both the CR's needs and the effectiveness of the AL and hospice in meeting those needs. This evaluation, in turn, influenced the caregiving activities and the intensity of the FCG's engagement in activities needed to maintain the balance between the CR's needs and the care provided.

Influences on Family Caregiver Activity and Changes Over Time

Graphing Caregiver Intensity

FCGs engaged in different activities to support the CR, and they did so at different levels of intensity. *Intensity of caregiving* refers to the amount of time and energy that a FCG spends providing and overseeing care, the nature of the FCG's engagement with formal providers, and the activities that the FCG engages in on behalf of the care recipient. Different levels of intensity were evident both when comparing different FCGs and when examining a single FCG's activities over time. Examining these intensity levels led to categorizing them as "low," "medium," or "high," based on the following criteria.

- *Low intensity.* Caregiving has a social focus, and is fairly limited and "hands off." Visits occur up to three times a week and are generally short. Oversight of the AL facility and/or hospice is limited. There is no attempt at or desire for contact with the hospice RN (HRN) other than that initiated by the HRN. The FCG may feel that their presence has limited effect on the CR's care or quality of life.
- *Medium intensity.* Caregiving activities appear to occur more often (3–5 times a week) and are more varied. Besides social aspects, there are more activities related to meeting the CR's desires, and not just their needs. Caregivers are much more likely to be directly engaged with AL facility and/or hospice staff, providing them with feedback, suggestions, and requests. While there is some oversight and monitoring of care, the FCG is not as directive with care as is the case with high-intensity caregiving.

- *High intensity.* Family caregivers are present every day or almost every day, often spending several hours with the care recipient. FCGs appear to be highly involved with the provision of care, either by directing care, overseeing care, or providing personal care themselves.

When graphing intensity of care, two strong patterns emerged. For some FCGs, there was a fairly steady downward trajectory from a higher level of intensity to a lower level. An example of this pattern is case #1, with family caregiver Lydia and her mother Donna. Lydia cared for her mother for over 15 years. After realizing that her mother's dementia was making it impossible for her mother to live completely independently, Lydia moved Donna into a house across the street from her. For six years, Lydia went to her mother's house multiple times each day to assist her with her activities of daily living. After those first six years, Lydia moved Donna to an AL facility. While living at the AL facility, Donna developed breast cancer, and hospice was engaged to monitor and manage her condition. Donna's dementia also progressed, and Lydia and her husband both experienced increased health issues. By the time I interviewed her, Lydia had made a deliberate decision to limit the time spent with Donna to a few short visits a week.

I was going up there about every other day for years, if not maybe every day... [I would] stay and visit for an hour or so. I probably do it only twice a week now. The reason is: number one is I'm starting to take care of myself 'cause I'm having lots of problems; and she doesn't know the difference...she's not really missing me...She's happy in her own little world. Nothing is really very important to Mother right now. Except herself. (Lydia, interview)

For other FCGs, there was a general increase in intensity towards the end of the care recipient's life (see Appendix D). An example of this pattern is case #3, involving caregiver Diane and her mother Sally. For many years Diane's involvement focused on

monitoring care and meeting social needs, occasionally punctuated by managing emergent health issues. As Sally's health declined, Diane found her mother's care required more of her time and energy.

It's becoming more of a multi-tasked thing. Instead of just going to get her and going to dinner and enjoying, you know, a little bit of time together... She seems to require me to come by or bring something... I used to call her maybe twice a week, and now it's pretty much every day. (Diane, interview #1)

Sally then experienced an "event" causing a dramatic decline, leaving Sally with limited neurological control and, eventually, bed-bound. After this sudden change in condition Diane spent significant time with her mother every day until her death a month later.

Several factors influenced the intensity of FCG involvement in care. These factors, definitions, and exemplars are described in Table 3.

Table 3

Factors Influencing Caregiving Intensity

Factor	Definition	Exemplars
FCG's appraisal of CR's needs and unmet needs	How the FCG interprets the changes in the CR's state of health in terms of changes in the CR's needs for help and support. If the FCG perceived there to be unmet needs, s/he would either arrange for others to meet those needs, or would supplement them him or herself.	<i>It's harder on her heart to breathe...and Mom's appetite has decreased some lately, She's not been eating as much...Thursday...her dinner was sitting right there...it's like she didn't want to make the effort to eat and so I took her plate and just helped- I just helped her eat...feeding her a little bit. (Kay, interview #1)</i>

Factor	Definition	Exemplars
FCG's appraisal of AL facility's response to CR's needs	The FCG's assessment of the ability or lack of ability of the AL facility to provide the level and kind of assistance the CR requires, even as the needs change. If the FCG perceived the AL facility as not meeting the CR's needs, s/he would either arrange for the AL to meet those needs, turn to other resources, or would supplement them him or herself.	<p><i>Now that they're here, I'm not stressed out about it anymore, because they're someplace where, they're getting all the help that they need. (Lisa, interview)</i></p> <p><i>If they cannot take care of him, if he is going to be all the time in bed or something....I don't know how it's going to be (Ileana, interview #1)</i></p>
FGC's appraisal of hospice agency's response to CR's needs	The FCG's assessment of the ability or lack of ability of the hospice agency to provide the level and kind of assistance the CR requires, even as the needs change. If the FCG perceived the hospice agency as not meeting the CR's needs, s/he would either advocate for the hospice to meet those needs, turn to other resources, or would supplement them him or herself.	<p>[Asked what helped the most in the last 6 months] <i>having [hospice] nursing care come in, oh my gosh, that was a huge, huge relief to me because I didn't have a good feeling about the facility being able to do for her...and by having Patty [HRN], and the aide, Dolores giving her her baths and stuff...that was, was, a huge, huge part in it. I'm glad I didn't have to move her: by Patty talking to them, convincing them that she could stay there as long as she had extra help...it was definitely her talking to them, saying it would be alright [that made it possible for her to stay] (Diane, interview #2)</i></p>
FCG's self-appraisal of role and abilities	The FCG's description of what they see themselves doing for the CR; the importance of what they do; and their comfort with caregiving and their skills related to providing assistance to the CR. If the FCG perceived their role and actions as central to the CR's needs being met, and placement maintained, s/he would engage in a higher level of intensity. If the FCG perceived his/her activities less central to the CR's care, the intensity would be less.	<p><i>I want to take the best care of her, and keep everything going. (Lydia, interview)</i></p> <p><i>I feel overwhelmed, I don't feel qualified to do anything medically, that I understand that well. (Diane, interview #1)</i></p>

Factor	Definition	Exemplars
FCG's appraisal of other family members' response to CR's needs	The FCG's assessment of the level of involvement with the CR and support that the FCG is receiving from other family members or from others who are involved in the CR's life. If the FCG perceived other family as available to assist in meeting the CR's needs, the FCG may use other family member's involvement as a way of lessening the intensity of their caregiving.	<p><i>My brother is there if I need him. And I don't ask him, because I know he has his own challenges, and I ask him only when I need him. And I think he appreciates that.</i> (Diane, interview #1)</p> <p><i>I wish they were all more involved, you know, you can lead them, but you can't force them.</i> (Tom & Debbie, interview)</p>
Competing demands on the FCG	Factors that may influence the involvement of the FCG in caregiving, including FCG health and other demands on FCG time and energy, such as work or family. Competing demands were often minimized as much as possible, but their presence could and did decrease the intensity of caregiving for some FCGs.	<p><i>It's hard for me to continually take off work; I don't want to lose my job.</i> (Diane, interview #1)</p> <p><i>I go there every day that I can. After work, in the evening, on the weekend. I don't go there every single day. I can't because I've so much to do.</i> (Raisa, interview)</p>
Family caregiver-care recipient relationship	The nature of the relationship between the FCG and the CR. The lack of a close relationship often precipitated a less intense involvement, while a close relationship led to a higher intensity of caregiving.	<p><i>My mother and I were not real close...I was just there in case she needed some help along the way. That's all I could do.</i> (Jay, interview)</p> <p><i>My mom and I used to be best friends, we used to go shopping all the time, and we could sit and talk for five hours.</i> (Lisa, interview)</p> <p><i>We've been married for 35 years and I love him but I just couldn't do it anymore.</i> (Sunny, interview #1)</p>

In order to understand the intensity of caregiving and the FCG's level of involvement, it is necessary to examine the dynamic tensions between what the FCG perceived the AL facility and hospice to be doing for the CR and what the FCG believed

needed to occur in order to ensure that the CR could successfully stay in their AL home until death. Integrating the factors listed above with the overarching goal and examining the interactions of all these elements led to the model illustrated in Figure 1 and described below.

Appraisal of the Care Recipient's Needs and Unmet Needs

The FCG's understanding of the CR's trajectory and prognosis influenced both the FCG's appraisal of the CR's needs and the FCG's activities on the CR's behalf. Although CRs were enrolled in hospice, not all FCGs voiced recognition that the CR was terminally ill or that death was approaching. This may have been related to the ambiguously terminal conditions of most of the CRs. The CRs in this study had chronic conditions and experienced gradual (and, at times, uneven) trajectories of decline that obscured their final prognosis: at the time of initial interviews, none of the CRs was actively dying or obviously dying. While FCGs could describe changes in the CR's condition, they were not necessarily able to link them to impending death, despite the fact that several of the participants died during the course of the study or shortly thereafter. The pattern of decline described by the FCGs contained clues that the FCGs could, in retrospect, see were indicators of a terminal condition. While the decline was in progress, however, these clues provided limited or ambiguous information to the FCG, in terms of both the CR's changing needs and overall trajectory.

This limited understanding of the nature of the CR's decline made it difficult for the FCGs to foresee the increased needs of the CR and the potential need to move to a higher level of care. For example, FCGs would comment on changes in cognition, but not

necessarily understand how these could impact care and safety needs, as was the case for a CR whose cognitive changes created problems regarding safety and self-transferring.

She had an incident where she was trying to get up out of her bed and she didn't make it and she was draped half over her bed...we don't know how long she'd been like that...she didn't know to push her button, she couldn't, so this happened. (Kay, interview #1)

Family caregivers who perceived that there were needs that couldn't be met through the combined effort of the AL facility, hospice, and other family members often tried to meet those needs themselves with a higher intensity of care.

Family Caregiver Responses to Changing Care Recipient Needs

Recognizing that the CR's needs were changing, FCGs worked to ensure that measures were in place to manage what the CR could no longer do on their own and to maintain placement and meet their needs. Sometimes FCGs increased the level of care provided by the AL facility; other times, they increased their own level of involvement with the CR. For the participants in this study, changing CR needs provided the impetus for adding hospice services, which were seen as a way to maintain the CR's residency in their assisted living home.

Family caregivers' understanding of the CR's disease process, prognosis, and needs influenced the amount of time that the FCG spent with the resident. Sometimes this led to shorter and less frequent visits, while at other times it led to more frequent visits or to more time spent with the CR during visits. Having an awareness of "limited time" was one explanation for the change. One participant, who also worked at the facility her mother lived in, put it this way:

I sometimes hesitate about stopping before I leave, but these days because

I don't know how much longer I have her, I always try and stop and say goodbye before I leave for the night (Kay, observation #2)

Family caregivers responded to CRs' increased needs by either providing the needed care themselves, or arranging for others (i.e., AL facility staff, hospice staff, other family members) to provide this care. The engagement of hospice was seen as part of the FCG's response to the changing needs of CRs.

The FCG's understanding and appraisal of the CR's changing needs created a lens through which the other factors (AL, hospice, the FCG themselves) were seen. These factors led to changes in FCG activities—activities that were directed at keeping the CR safe, comfortable, and in their current setting.

Appraisal of Assisted Living Facility's Response to Care Recipient's Needs

Family caregivers often saw assisted living facilities as an imperfect solution, but preferable to the alternatives: the CR staying in an unsafe setting (one that was no longer able to meet the CR's needs) or their being placed in a nursing home.

She lived at home by herself...and she fell down and that kind of sent up a red flag. And we said we need somebody up there, and it didn't go real well. She had problems with the people that we had up there taking care and everything...and at one point we just decided that that wasn't going to be good enough. We need to do something different. So, we looked at assisted living, and that's how she ended up going into assisted living. (Tom & Debbie, interview)

While general satisfaction with the AL ranged from fairly dissatisfied to a mainly positive appraisal, study participants generally felt that the facility their family member lived in was an appropriate setting for the CR and that it was able to provide care that met the CR's needs. Even in the case of the participant who had the greatest number of

complaints, there was a sense that the move was for the best.

Now that they're [CR and husband] here, I'm not stressed out about it anymore, because they're someplace where they're getting all the help that they need. (Lisa, interview)

All of the FCGs expressed an understanding of the limitations inherent in the facility in which the CR resided and in the limitations of AL in general. Many of these comments centered on staffing. On one hand, FCGs would prefer more staff; more highly trained (and perhaps better paid) staff; and staff that had more time for individual residents. On the other hand, FCGs recognized that fulfillment of these desires was not feasible in the AL setting. These statements may reflect the FCGs' pragmatism, but they could also show how FCGs adjusted their expectations and priorities in order to be more comfortable with an imperfect situation.

But I don't think [facility] is any different than any of the others, I really—I mean I'm not just singling out that place. I think it is the same all around. One place is not going to be any different than the other. (Lisa, interview)

Most important in the FCG's appraisal of the AL facility was the AL facility's ability to continue to meet the CR's needs as their health continued to decline. In some cases, the FCGs expressed confidence in the facility's ability to continue to provide appropriate care to the CR until death.

I think that they pretty much give any level of care even if you're bed ridden. Down there they will give you that level of care. (Tom & Debbie, interview)

While generally assured of the AL's commitment to maintaining placement, caregivers had mixed appraisals of the AL facilities' ability to meet the CR's ongoing needs. Some had high confidence in those abilities, while others felt less certainty. The addition of

hospice was viewed as another opportunity to fill the unmet needs of the CR and, therefore, allow the CR to stay in their AL home.

Impact of Appraisal of Assisted Living Facility's Response on Intensity of Family Caregiving

The intensity of family caregiving was influenced by assessments of the AL facility's ability to meet the CR's needs and the care that the CR received. The more positive the FCG felt about the facility and the staff, the more trust was engendered and the less vigilant the FCG felt they needed to be.

During an observation, asked participant how he engages with either the assisted-living staff or the hospice staff: *"I trust them to do their job and to call me if there are things that need to be dealt with or if things change."* (Jay, observation #2)

Much of the FCG's focus was on the skills and abilities of the staff.

There is a lady, I really trust her, she is very good...She does this 34 years. She is a bright woman, she is the best, I think...She knows what she is doing, and if I cannot take out Sasha's teeth she can. She talks to him, you know, she is good. (Ileana, interview #1)

FCGs' appraisal of staff is also reflected in their level of involvement. Those who were comfortable with the staff were more likely to be less involved, while a lack of confidence may have motivated a higher level of caregiving. In the most extreme case, the FCG was an almost constant presence at the AL facility. She was aware that it was impossible for the AL facility to provide the same level of care for her husband that she could. As she came to know the staff better and perceived them as responding to her concerns, however, even this FCG became more willing to leave her husband's side on occasion, to have lunch with a friend or to see her church counselor. The only other

spouse in the study responded very differently to having her husband in AL. Perceiving the AL facility as providing her husband with competent care, she took a more hands-off approach:

I need to back off and let them do their thing...I think once I can just back off and let go that I won't have to worry about him...I expect it to be where I can just go up there and visit him and do things with him...and just be able to enjoy our time together instead of me trying to do things and getting all frustrated by him. (Sunny, interview #1)

Whether the impression of the AL was generally positive or negative, the FCG's appraisal of the AL facility's ability to respond to the CR's changing needs and maintain the CR's placement while providing appropriate care influenced the intensity of the FCG's caregiving activities.

Appraisal of Hospice Agency's Response to Care Recipient's Needs

In general, the FCGs had very limited knowledge of hospice before that entity became involved with the CR's care. There was a general lack of knowledge of what hospice did, who the individual members of the hospice team were, or what their functions were. While almost all study participants were present at the hospice intake, this process did not ensure that they understood what hospice does or does not do, or what form interactions between the FCG and hospice personnel would take. As one participant put it: *"I just think we didn't know a lot of questions to ask"* (Diane, follow-up interview).

Hospice was often presented and/or perceived by the FCG as "extra help" that would allow the CR to continue to reside in their AL home, thus linking hospice to the FCG's overarching goal. No matter the mechanism or reason for engaging hospice,

however, it is clear that hospice played an integral role in maintaining the CR in their AL home, both by providing a higher level of care than would otherwise be possible in this setting and by relieving family caregivers of some of their burden and stress.

Hospice was commonly perceived as a supplement to the care provided by the AL facility—a way to fill gaps in care and achieve the FCG’s overarching goal. The additional services provided by hospice helped with the financial aspect of this goal, and included necessary medications, supplies (such as hospital beds and lift chairs), and services (such as a higher level of medical oversight, massage, and psycho-social supports).

*Just having that nursing care come in, oh my gosh, that was a **huge, huge** relief to me because I didn’t have a good feeling about the facility being able to do that for her...I just always wondered about how much attention they would actually pay to her, and by having Patty [HRN], and the aide, Dolores giving her her baths and stuff, that was....and Mom was happy with that, ya know, she....so to me that was, was, a huge, huge part in it. (Diane, follow-up interview)*

One of the qualities that FCGs noted about the hospice team was their responsiveness, especially in terms of their ability to meet the changing needs of the CR. Whether it was attending to a specific crisis, handling the ongoing issues that developed as part of the terminal decline, directing complicated treatments (such as diuresis) on an individual with multiple morbidities, or managing the final dying process, the hospice team—in particular, the hospice RN—made a clear difference in the ability of the CR to die in their AL home.

She [HRN] came very often, I don’t remember exactly, but last day, she spent, she was there with me two hours...she exactly explained it to me how he’s going to breathe and he coughed, he was coughing the day

before, so Leslie right away ordered some drops under his tongue so it would make it easier to breathe, I don't know what was it, and then, the day he passed away, they were giving to him every 15 minutes some morphine, just to keep him comfortable. (Ileana, follow-up interview)

In general, the FCGs' appraisals of hospice were overwhelmingly positive.

Hospice was seen as competent, and as meeting the FCGs' expectations. Furthermore, FCGs were particularly impressed with the compassionate and respectful manner of hospice personnel, and with their individualized approach to end-of-life care.

I [was]....so amazed how Patty dealt with my mom, cleaning her up and giving my mom a hug and kiss right afterwards. And, you know, to me it was, that was just marvelous. And she just had respect for my mom, even though my mom was going through all that, you know. And I know she felt it. I know she could feel that, you know.... could feel that Patty cared. (Diane, follow-up interview)

Impact of Appraisal of Hospice Response on Intensity of Family Caregiving

Considering the generally positive impression that FCGs had of hospice and hospice involvement, it is not surprising that the addition of hospice had a strong influence on the family caregiver's activities and on their appraisals of the CR's ability to maintain placement. FCGs often expressed their feeling that they had an ally in the hospice team, who would be able to manage the CR's needs and work with the AL facility to ensure their care.

All of these factors helped the FCGs feel more confident in the care that their family member was receiving, and provided the FCGs with supports that allowed them to continue in their role as caregiver:

I think it's wonderful. I really do. I mean, the support that is there for her, for me, for my dad, 'course my dad doesn't think he wants any support. But Jennifer has given him support whether he wants it or not...I think he

feels that part of the load is off of him because of Jennifer. You know, he's not so stressed out as he was before, you know trying to, he and I trying to be the only people to deal with her, because she was getting pretty difficult before hospice took over. And so, there's been a lot of pressure taken off of him, because of Jennifer. And, you know I think that's why he likes her so much. [laughs]. Because he's not--he feels like he is not alone in this anymore. (Lisa, interview)

These factors also allowed some FCGs to be less involved.

He (Jay) trusts them to let him know what's going on and to pretty much make the suggestions of what needs to happen, because it's stuff he does not know anything about. (Observation field notes, observation #2)

Communication was a very important factor in the interactions between the FCGs and hospice and AL staff. Unlike their mixed reports about communication with the AL staff, the FCGs felt that the hospice RNs maintained direct lines of communication with at least one family member, if not more. These links increased the FCGs' ability to understand the CR's situation, changes, and trajectory in a way that would not have been as likely to happen without the hospice RNs' involvement, thus giving FCGs the confidence that would allow them to pull back from caregiving.

Family Caregiver Self-Appraisal of Role and Abilities

The FCGs' level of involvement depended, in part, on their assessment of the AL facility's ability to meet the CR's changing needs. When the CR's needs could not be met by the combination of AL and hospice care, the FCGs often saw themselves as being responsible for filling those gaps in care, particularly if they wished to avoid transfer to a nursing home.

You have an obligation. It's as simple as that. You have an obligation, you can say "why me?" Me? Because I'm here, I mean it's as simple as that, I mean, you don't worry about it you just do it, I mean... (Jay, interview)

FCGs' appraisal of their role and abilities varied. At one end of the spectrum was the family caregiver who put every other aspect of her life aside while the CR was declining, feeling that her presence was necessary for the CR to receive adequate care:

[Observation field notes] *For now, the place she needs to be is here with Sasha. More than once, she says "who would take care of him if I was not here?" ... Ileana cuts up the meat smaller, commenting "How would he eat if I wasn't here?"* (Ileana, observation #3)

At the other end were the FCGs who were less intensely involved in care, perceiving another FCG as the primary caregiver.

I'm comfortable with talking to Kay [primary CG] about it and having her being at the point. I figure it's more of a tandem point, you know, financially and, you know, I have enough responsibilities. (Tom & Debbie, interview)

Two of the FCGs in this study were spouses who had been highly involved with providing hands-on care prior to AL placement. For these individuals, it was a challenge to relinquish that responsibility.

Part of it was that I thought I could do it myself; I've always been one who could do things myself. (Sunny, interview #1)

For both of these spouse caregivers, an outside individual had to provide encouragement and support for the move to the AL facility and for subsequent relinquishment of care:

the kids convinced me, I cannot take care of him. (Ileana, interview #1)

As the CR's needs changed over time, many of the FCGs in this study saw that their role needed to change as well. Some caregivers moved from a more social role into a role that involved more monitoring of the CR's condition:

All she's [CR] ever talked about, is her health, and so we just [in the past] tried to ignore it, and now I'm having to really try to pay attention [to her

complaints], *and see if there really is something the matter.* (Diane, interview #1)

Others who had been very engaged in caregiving saw the changes as a time to move back from a hands-on role to one that was more social:

I just have to back off and let them do it and just go in and be there and be with him and not try to do anything for him, physically, anyway. (Sunny, interview #1)

A common theme among several of the FCGs was their constant awareness of the CR and their needs. Whether it was a matter of feeling like they could not go away for any length of time, or of having the CR and their needs be constantly on their minds, the CR clearly occupied a central place in the FCG's life, routines, and psyche.

None of it is hard –hard, but it's just that it's always there. She is always on my mind. Always on my mind. The telephone rings late at night, or you know, I immediately think it's something. (Lydia, interview)

As the FCGs changed their activities and saw their role shift because of the CR's declining condition, they expressed a range of awareness of the changes being experienced by the CR. Sometimes this awareness was expressed in terms of a general understanding of the "inevitable":

We know where we stand, we know what we have to do, we're not a couple of people who leave things to the last minute and so forth [chuckle], hoping something will go away, I mean, we know the inevitable is just around the corner. (Jay, interview)

The FCGs adjusted their interactions with the CR in response to changes in the health and condition of the CR, including changes in the CR's energy level, function, and/or cognition. Family caregivers' awareness of changes in the CR and the FCG's responses to changes varied; however, the overall FCG reaction was greater attentiveness to the CR

and their needs.

No matter the particular activities that they engaged in, or how intense their caregiving was, all the FCGs in this study saw themselves as a vital part of the CR's life and care, and as an important factor in the CR's being able to stay in their current setting:

Mom wasn't having a good day...if something's not right with her I want to know and stay with her... if her heart is acting up and she's having a hard time breathing I want to be there. (Kay, interview #1)

The family caregiver's self-appraisal of their role and abilities had a direct impact on their caregiving, both in terms of what they did and the intensity of their activities. Seeing themselves as central to the CR's well-being (or, in one case the well-being of the primary family caregiver) kept them engaged even if they were conflicted about doing the work. Family caregivers may have viewed the AL facility as the primary source of care provision, and hospice as a "gap filler" who made it possible for the CR to stay in their ALF home, but the FCGs saw a need to be present to manage and oversee the care – and if they saw the CR's needs as not being met, to do what was necessary to make sure they were. The FCG's vision of what needed to be done and how to best accomplish the overarching goal was colored by the activities the FCG felt comfortable engaging in.

Other Influences on Caregiving Intensity

The intensity of family caregiving was influenced not only by the FCG's appraisal of the extent to which the CR's needs could be met by a combination of AL facility and hospice services, but also on the ability of other family members to be involved, an assessment of the competing demands on the FCG, and the quality of the FCG-CR relationship.

Family Caregiver's Appraisal of Other Family Members' Response to Care

Recipient's Needs

In this study, there was generally a clearly delineated primary family caregiver. Other family members' involvement with the CR varied, and the locus of caregiving sometimes shifted over time. The FCGs' appraisal of other family members' limited involvement paralleled the FCGs' sense that they were the primary (if not the only) person responsible for the CR. Perhaps because of this appraisal, the FCGs in this study had very limited expectations of other family members' involvement.

Family involvement in care varied greatly. While some were quite engaged, collaborating on caregiving, others were less engaged, making visits when they could or for special occasions and being more of a support person for the primary FCG. In some situations, other family members were either not involved at all or were not involved to the degree that the primary FCG would have preferred.

I wish they were all more involved, you know, you can lead them, but you can't force them. (Tom, interview)

The nature of the relationships between the primary FCG and other family members influenced the FCG's expectations of how other family should be involved in caregiving. In general, FCGs were very understanding of the lack of involvement of other family members. This may be related to the FCG's self-identification as the person responsible for managing the CR's care. Whether because of relationship, history, personality, location, or availability, the primary FCG's assessment was that they were the person best able to fulfill the caregiving role. FCGs often provided explanations for the lack of involvement by other family members.

But, it's not feasible for any of my kids, you know my daughter, she has two young children. And living in Seattle, she's just-- there's nothing she can do, other than come and visit, and call them on the phone. So, and then my two sons, they can't do anything either, I mean, as far as being a caregiver, there's nothing they can do. (Lisa, interview)

Competing Demands

All of the family caregivers had to deal with competing demands, which in some cases interfered with their ability to care for the CR in the way that they would have preferred. For some FCGs, work or other outside obligations competed for time and attention given to the CR.

It's hard for me to continually take off work, I don't want to lose my job...I'm sure they'd be very flexible with me, but, there comes to a point, you know, when you know they can only do that so often. (Diane, interview #1)

Other caregivers seemed to struggle to find the right balance between attending to their own needs and providing care to the CR.

It's too much. It's overwhelming, everything, trying to take care of everything... just kind of like the bowl is spilling over...it means cutting some things out of my life. I'm not doing the things I usually do as much as I used to. I'm not keeping my house as clean. I'm not cooking as much. I'm not taking care of the kids as much. I'm not riding my bike as much. It's affecting everything. And, it's not just that that is affecting it, it's everything else is affecting everything else. (Raisa, interview)

No matter how an FCG managed competing demands, the fact that their loved one was in an AL facility and—perhaps even more importantly—that hospice was involved in their care provided the FCGs with a sense that they could decide whether to be more or less involved. No matter the intensity of their involvement, however, the FCGs appear to have understood that some level of involvement and oversight was required in order to

ensure that the CR could remain in the AL setting. In balancing the different forces competing for their energy and attention, FCGs generally appeared to put the most importance on doing whatever was necessary to ensure the CR's continued AL residency, even if that goal had a negative impact on the FCG's health or other obligations.

No matter how the FCGs responded to competing demands, the involvement of hospice and (to some degree) the AL facility allowed some FCGs to feel comfortable in stepping back, as they felt assured the CR's needs would be met even as those needs changed.

Caregiver-Care Recipient Relationship

Relationship history and prior ways of interacting appear to have had an influence on how close or distant the FCG felt towards the CR and, therefore, influenced the FCG's appraisal of how much they *should* be involved in caregiving. Prior to AL placement, some of the relationships were clearly close. In contrast, however, some FCGs were very frank about the lack of closeness they felt for their family member, even when that emotional distance was not recognized or acknowledged by the care recipient.

My mom and I have never been close...I don't share my personal desires and any of that stuff with my mother... she doesn't see that we're not, I mean she thinks that we are. (Diane, interview #1)

For some of the FCGs who were not historically close with the CR, there was nonetheless a long history of involvement in their family member's care.

I have been taking care of Mom for 30 years as far as being the person who's around and I mean I'm the one who takes her to the doctor and so forth. (Jay, interview)

Prior to the CR becoming seriously ill, relationships ranged from very close to

fairly distant. While some of the relationships did not change, others did. Changes included close relationships becoming closer, and relationships that were not so strong being strengthened through the process of providing care.

My mom and I have never been close... so I think that this has been good for me because it's helped me to understand my mom a little better, help maybe bring us together a little bit more towards the end. (Diane, interview #1)

In some cases, relationships became more distant. This might be related to the change in role—from spouse to caregiver, for example—or it may relate to the loss of routine and of normal ways of having social interactions (such as an end to shared pleasurable activities).

My mom and I used to be best friends, and we used to go shopping all the time, and we could sit and talk for five hours. But, you know she can't-- she just can't carry on a conversation. I mean, you ask her something and she'll answer you, but as far as carrying on a conversation, she, it's hard for her to do that. (Lisa, interview)

Cognitive changes—particularly ones that affected the ability of the CR to have social discourse and meaningful interaction—changed the nature of FCG-CR relationships and directly influenced the intensity of caregiving. For example, an FCG's recognition that the CR did not notice when she was absent became a signal that it was permissible to pull back.

She doesn't know the difference....it bothered me that I wasn't spending time with her and stuff. But it got to a place where I could be gone on that little trip with my husband, be gone a week and I'd walk in and she'd say "oh, I didn't expect you today." (Lydia, interview)

From the FCG's perspective, the absence of a current meaningful relationship with the CR may have allowed or compelled them to rely on others to provide care.

All participants, no matter how close or distant, were engaged with their caregiving role. It is not within the scope of this study or analysis to delve deeper into motivation or impetus for care, but all participants spoke about their caregiving in terms of responsibility and obligation.

I just feel it's, I, you know, I think it's my responsibility, I'm her daughter that's what I should do, um, I just can't imagine not doing that for my mother, you know? (Diane, interview #1)

It is possible that, in the absence of closeness, a sense of duty precipitated a lower intensity of caregiving activities, while a close or meaningful relationship led to a higher intensity of caregiving.

The family caregivers in this study were all engaged with their dying relatives' care. They all wished to avoid moving the CR out of the AL facility and into a nursing home. The FCG's appraisal of the care recipient's met and unmet needs and of the ability of the AL facility, hospice, and (to a lesser degree) other family members to meet those needs influenced the FCG's activities and the intensity of their caregiving. This assessment developed through ongoing monitoring and surveillance of the CR's trajectory and needs, and through an appraisal of how effectively the care provided would maintain placement. These evaluations directed the FCG's response, both in terms of activities undertaken and the intensity of their involvement. The FCG's response was influenced to some degree by competing demands and the nature of the relationship between the CR and the FCG. This iterative process and the overarching goal framed the family caregivers' responses and created the pattern of caregiving intensity over time.

Chapter 5: Discussion

The family caregivers (FCGs) who participated in this study shared a common goal for their dying family member: They all hoped that their loved one would be able to live out their remaining days in the assisted living (AL) home and, most particularly, that they would not have to be moved to a nursing home. Mapping out the intensity of caregiving engaged in by family caregivers illustrated how the caregiving intensity of individual family caregivers varied over time and how patterns of intensity differed from one FCG to another. The two patterns that emerged were one that involved a steady downward trajectory, and another that showed more variation over time, ending with increased intensity. The existence of these patterns led to an investigation of what might be influencing them. Family caregivers weighed their perception of the care recipient's (CR's) needs against the ability of the assisted living facility and hospice agency to meet those needs and, to a lesser degree, the ability of other family members to meet them. This evaluation prompted the family caregiver to step in to fill gaps and ensure the well-being of their loved one. The efforts of those participants who were followed through the death of the care recipient were generally successful—none of the care recipients was relocated to another setting, the deaths were well managed, and the family caregivers expressed satisfaction with the care their loved one received and the way in which they died.

While supporting and confirming prior research, this study makes some important and unique findings. While other studies have explored the activities of family caregivers of assisted living residents, this study focused on the experience of the family caregivers

themselves, and exploring the unique needs of family caregivers involved in end-of-life care for aging family members, the challenges to providing that care, and the factors that influence the goal of maintaining AL placement until death . Like prior studies (Ball et al., 2004; Cartwright & Kayser-Jones, 2003), this study illustrates how family caregiver involvement can be a crucial element for maintaining placement of an AL resident at end of life. However, this study extends our understanding of how the FCGs' concerns and perceptions influence their activities and the intensity of their involvement. This information can help guide the actions of assisted living and hospice staff who provide end-of-life care in assisted living.

This study also highlights another way that FCGs managed their response to provision of care. Even when they voiced complaints about the care provided by the AL facility, the FCGs' comfort with the situation sometimes increased through a process of managing expectations through reframing. Sometimes the reconciliation of conflicted feelings occurred by accepting "trade-offs"—bearing what was previously unacceptable by focusing on other positive aspects of care. Other times it was a matter of settling for what was possible and comparing it to the perceived negatives of relocation. In this way the FCGs were able to balance any misgivings they had about the setting and accept aspects of care that were less than desired.

Knowing the contextual factors for family caregivers can assist in communication between formal and informal caregivers, help in understanding the FCG's perspective, and lead to more effective collaboration and congruent expectations regarding roles and potential outcomes among the involved parties.

Situating the Study within the Current Literature

By articulating the overarching goal of the participants, this study helps to fill a gap others have identified regarding the responses of AL residents and their families to having to relocate a CR from AL to a higher level of care (Kelsey, Laditka, & Laditka, 2010; Rosenberg, et al., 2006). The study supports the extant literature about the attitudes of AL residents and families toward aging in place in AL. As in other studies, residents and families describe the AL facility as “home” and express the desire to age in place/die in place (Ball et al., 2004; Cartwright & Kayser-Jones, 2003; Mead, Eckert, Zimmerman, & Schumacher, 2005). As in this study, participants in other studies acknowledged that a move to a nursing home was an unwanted but real possibility, and efforts were made to delay or forestall such an occurrence (Cartwright & Kayser-Jones, 2003; Castle, & Sonon, 2007; Mead et al., 2005; Stone & Reinhard, 2007). Also apparent is that, as concluded elsewhere (Cartwright, Miller, & Volpin, 2009; Dixon, Fortner, & Travis, 2002; Mead et al., 2005), the FCGs’ efforts were instrumental in the CR being able to stay in their AL home until death.

Highlighted by this study is the family caregivers’ constant awareness of financial pressures. Despite the availability of Medicaid waivers, the majority of AL residents are private pay (Stone & Reinhard, 2007). Furthermore, AL costs are not constant, but are based on the amount of supplemental assistance that the resident requires. While hospice does provide support by supplying some equipment, supplies, medication, and additional personnel, increased costs as the CR’s health declines are almost inevitable. When combined with the uncertain trajectory of many of the CRs, these increasing costs make

concerns regarding money and solvency quite understandable. These concerns are not unique to this study; they are also voiced by participants in other studies (Kelsey et al., 2010; Kemp, 2012).

In this study, family members were involved at diverse levels and in a range of activities similar to that described in previous work (Ball et al., 2004; Gaugler & Kane, 2001; Munn & Zimmerman, 2006; Port et al., 2005; Wright, 2000). While family caregivers were involved in a number of activities, the highest impact came from actions related to monitoring the CR's health status and the quality of their care, and from acting as an advocate for the care recipient.

Though approaching the subject somewhat differently, this study parallels other end-of-life and caregiving studies in the use of trajectory as a framing device. Often cited are Lunney, Lynn, Foley, Lipson and Guralnik (2003), who provided an empirically based theory of end-of-life trajectories. More recently, a model of family caregiver trajectories was produced by Penrod, Hupcey, Baney and Loeb (2011). Creating a visual representation helps to reinforce the continuous nature of caregiving, rather than allowing it to be perceived as episodic.

Study Limitations and Strengths

Study Limitations

The study's main limitations relate to the sample, which was extremely homogeneous regarding race and ethnicity—all of the participants were “white not of Hispanic origin.” This homogeneity accurately reflects the demographics of AL facilities and hospice. According to Stevenson and Grabowski (2010), AL facilities are present

most often in areas with higher educational attainment, income, and housing wealth, and provide limited access to minorities. As a result, hospice has traditionally been utilized by very few ethnic and racial minorities. In the state where the study was conducted, over 93% of the patients were white (Jackson, 2007). Still, it is anticipated that the growing numbers of older adults in the US will become more ethnically and racially diverse over the next two to three decades, and the number of Hispanic, Asian, and African Americans in NHs is on the rise (Feng, Fennell, Tyler, Clark, & Mor, 2011). Therefore, research into what may be the unique needs of older adults of color in AL is needed.

Further limitations were the limited number of AL sites (two independent facilities and two facilities belonging to the same chain), and recruitment via just two hospice agencies. Additionally, all of the care recipients were private pay, even though all but one of the facilities accepted Medicaid waivers. It should also be noted that the hospice length of stay statistics for the sample were atypical: While the mean length of stay for patients in foster care, residential care, or assisted living in the state was 15 days (Jackson, 2007), the mean for this sample was approximately 180 days. Consequently, the perceptions and responses of the FCGs in this study may not reflect those of individuals with a more limited hospice experience.

Another study limitation was the lack of consistency in data gathering: I was not able to observe all of the family caregivers while they were interacting with the care recipients in their AL facility, nor was I able to follow all the FCGs through the CR's death. I was able to conduct follow-up interviews with only four of the ten participants,

although I maintained phone contact with one other participant and received updates regarding the CR's status and changes in care.

The potential for selection bias must be acknowledged. Participants were recruited through hospice RNs (HRNs). Three nurses provided all of the participants, with two of them providing the bulk of the participants. It is impossible to know what criteria (beyond the admission criteria of the study) were applied by these individuals before they approached potential participants. Finally, as was noted in earlier chapters, AL is regulated at the state level, making results potentially less transferable to other locales.

Study Strengths

Despite the study's limitations, there were several notable strengths. The sample was quite diverse in some aspects, even with the limited number of participants. The study encompassed both male and female family caregivers as well as male and female care recipients. The age range of the family caregivers was wide, ranging from 48 to 85. The age range of the CRs was also fairly broad, ranging from 68 to 105, and encompassed the “young-old” (65–74), “middle-old” (75–84), and “oldest-old” (85 and older). The study included FCGs who were working both part-time and full-time, as well as those who were retired. Participants' incomes spanned several categories, from individuals who made \$20,000 to \$34,000 a year through those with annual incomes over \$100,000. The ability of the FCGs to manage on their income ranged from “I have just enough, no more” to “I always have money left over.” Relationships of participants to their CRs varied as well: there were spouses, sons, daughters, and a daughter-in-law. The

inclusion of more than one family caregiver for two of the cases also added depth and nuance to the data.

Prolonged engagement was another strength of this study. I was able to follow the CG-CR dyad as the CR experienced decline and new concerns and issues arose. I also had opportunities to revisit information shared by the participants in order to achieve clarity and better understanding. Finally, using both observation and interviews for data collection was a strength, creating a richer and stronger data set.

Implications for Practice and Policy

Implications for Practice

This study illuminated a number of practice implications. It became clear early in the data gathering process that family caregivers “don’t know what they don’t know.” Because the opportunities for hospice RNs to interact with FCGs is often limited, it can be difficult for the HRNs to determine the degree to which an FCG understands the CR’s current state, prognosis, and current or future needs. This lack of understanding of the dying trajectory is an issue (identified by Forbes, Bern-Klug, and Gessert [2000] and others) that highlights how important it is for HRNs to make ongoing efforts to maintain contact with FCGs, as well as the related need for ongoing assessment of the FCG’s needs for information and support.

Crucial to assessing the FCG’s information needs is an appreciation of the family’s understanding of the CR’s end-of-life trajectory. Even when enrolled in hospice, patients and families do not necessarily think in terms of terminality. This is understandable, particularly when dealing with chronic, life-limiting illnesses, as changes

are often incremental and subtle. It is important that healthcare professionals be able to provide pertinent and helpful information regarding prognosis and health changes, while also recognizing that words and disease manifestations do not necessarily have the same meaning for families as they do for health care professionals. Understanding these variables and dynamics can help healthcare professionals provide a framework for working with families and patients experiencing a terminal decline in the AL setting.

Cognitive changes that can accompany chronic illnesses are another aspect of the CR's trajectory that can be both poorly managed and poorly explained to the FCG. These cognitive changes can make it a challenge to maintain an AL placement. Family caregivers of individuals who are experiencing cognitive changes—particularly non-dementia-related changes—need information and support to help them make the best possible plans and adjust their expectations for the CR as concerns judgment and social interaction.

Recognizing that families and AL residents usually resist transfer to a higher level of care, it would behoove AL facilities to provide adequate and ongoing training and education to AL staff who are involved in end-of-life care. For many of the FCGs, the addition of hospice was seen as a way of maintaining placement—as a “gap filler.” In light of this perception, AL facility staff, the HRN, and the FCG need to have dialogue regarding the CR's status, needs, and goals, and about the role and scope of hospice care.

Implications for Policy

Issues regarding the conditions when a resident should be transferred to a higher level of care create major policy challenges. As other studies have noted, assisted living

facilities' relocation policies are often vague or nonexistent (Kelsey et al., 2010; Munroe & Guihan, 2005; Stone & Reinhard, 2007). Furthermore, even when a policy is explicit, it appears that situational considerations can carry more weight than the written policies, which creates even more uncertainty for the resident and their family.

Assisted living policies may need greater scrutiny to ensure that they accurately reflect the ability of the facility to provide adequate and appropriate care: Are AL facilities promising more than they can deliver? Is the issue one of pressure from residents and/or their families expecting (and sometimes demanding) more than the AL facility can safely provide? Two forces (at least) are keeping residents in AL facilities. The first is the desire of AL administrators to keep their occupancy rates stable—an important consideration in these difficult economic times. The other is the aversion that both residents and families have to nursing home placement. One way to manage this situation would be to provide more complete and accurate explanations of what the AL can do (including the related costs) so that families can make appropriate risk/benefit assessments.

Also bearing examination are the impacts of recent changes in the Center for Medicare and Medicaid's Conditions of Participation (CoPs) and other actions related to stemming Medicare waste and fraud. AL staff who present hospice to families as a "gap filler" may create untenable situations, given the increasing scrutiny of possibly inappropriate referral to hospice and excessive hospice lengths-of-stay.

One of the new CoP provisions is a requirement that hospice physicians or nurse practitioners have a face-to-face encounter with Medicare hospice patients prior to the

180-day recertification and before every recertification thereafter. It is not known what impact this requirement might have on communication between the hospice agency and the family, or on the FCG's understanding of the CR's condition and trajectory, but it is a change that should be monitored.

This study highlights the shift in terminal diagnoses of hospice-enrolled patients. Cancer, with its fairly predictable trajectory, was initially the only condition that would qualify a patient for hospice. As a result, cancer is the disease that the hospice model was based on. Currently, approximately 40% of hospice enrollees nationally have a primary diagnosis of cancer. In Oregon the number is closer to 35%. Only one of the CRs in this study was enrolled in hospice for cancer rather than for a chronic, life-limiting illness. Chronic illnesses are much more ambiguous, making it much harder to identify the terminal phase when hospice is appropriate. Understanding how and when hospice referrals should occur is an ongoing challenge.

Summary

This study looked at the experiences of family caregivers at end of life within the context of assisted living. These FCGs were engaged and involved with their loved ones' care, with varied levels of intensity. Intensity of caregiving changed for individual FCGs over time, and had different patterns among the FCGs. Several factors affected the intensity of the FCG's caregiving, which was performed with an overarching goal of maintaining placement and avoiding relocation to a nursing home. These major points are the most compelling results of the study, but there are other attributes of the study that are worth mentioning:

This study presented information about family caregiving in a number of important ways. Family caregiving is often depicted in the literature either cross-sectionally or episodically. This study reinforced the path forged by other researchers by presenting family caregiving as a continuum that occurs over time, illustrating what changes, and hypothesizing elements that may influence these changes. Furthermore, most literature about family caregiving at end of life focuses on the FCG's perceptions of the quality of care. This study highlighted the centrality of the FCG's perception of the CR's end-of-life care needs, their perception of the adequacy of efforts to meet those needs, and how that perception influenced what the family caregiver did in pursuit of their overarching goal.

Implications for Future Research

A continuing issue in end-of-life research is how to define "end of life" in studies. Defining it by hospice enrollment is convenient but limiting, particularly with regard to chronic conditions and the frequency of late enrollment. Recognizing the importance—and current lack of—longitudinal studies of family caregiving, it would be worthwhile to develop studies that follow individuals from AL admission until death or transfer. This design would better illustrate changes in FCGs' role, caregiving intensity, and comprehension of CRs' needs.

This study also presents opportunities for a number of follow-up studies. Studies of similar design that encompass a larger sample from a wider range of subjects, a larger geographical area, and longer engagement could provide more insight and deeper understanding of the subjects and setting. One way that longer engagement could be

particularly useful would be to follow those residents who are transferred out to their new locations in order to better understand the effects of their transfer on the quality of care and quality of death, as well as the impact on the family caregiver.

Another way to expand on this study would be to include the hospice RN, the AL RN, AL administrator, and other AL staff as participants along with the family caregivers and care recipients. This would facilitate a more complete understanding of the interplay between the different actors and better identify the strengths of and gaps in AL-based end-of-life care. Another approach would be to convene focus groups of all the involved parties—family caregivers, care recipients, AL RNs, AL administrators, AL direct care staff, hospice RN, and other hospice providers—and have the participants explore their perception of the challenges involved in providing end-of-life care while incorporating FCGs as both partner and client.

Hospice defines itself as “patient focused and family centered.” One of the challenges of providing end-of-life care in assisted living is incorporating the “family centered” aspect of the hospice. It may be unrealistic to expect hospice RNs to dramatically increase their engagement with families. Consequently, it may prove beneficial for a different person on the hospice team to be designated as “family liaison” when the patient is in a congregate housing setting, thus giving FCGs another point of contact. These “family liaisons” would be able to provide a fuller assessment of FCG needs, and be charged with either working directly to meet these needs or helping the FCG access appropriate resources. A tailored intervention would be a way of exploring this as a potential solution for keeping family caregivers “in the loop.”

This study highlights the variation in family caregiving when the individual lives in assisted living and has hospice. All of the participants in the study wanted their family member to stay in their AL home until death. In several cases, this goal was achieved, the care provided was adequate, and the ultimate quality of death was high. Recognizing this goal and the attendant concerns of the FCGs can be helpful to AL facilities and hospice agencies providing end-of-life care. Communication and differing expectations continue to be a challenge, whether these are between different providers or between providers and families. An understanding of the needs of the dying resident, the capabilities of the various providers, and the general costs and benefits of continuing in the AL setting is not always conveyed to families. Preparing families for what may come and explicitly discussing options and courses of action among all the relevant parties may help both families and AL residents achieve this goal without sacrificing quality of care.

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Appendix A

Review of the Literature Tables

Table A1 Qualitative Research on Aging and End of Life in Assisted Living

Authors	Study Design	Sample Size & Type	Purpose of Study	Major Findings	Comments
(Ball et al., 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 hr 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	<p>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</p> <p>Two types of strategies to manage decline: those aimed at preventing further decline and those focusing on response to decline.</p> <p>Managing decline often = managing risk, for both resident and institution.</p> <p>Resident Characteristics Most experienced inevitable decline</p> <p>Discharges r/t confused, disruptive or risky behavior 2/2 dementia or mental illness</p> <p>EOL Care not discussed</p> <p>Family Role Described as “support.” Specific examples provided Family as key to maintain residence</p> <p>Staying in AL Most residents and families wanted the resident to be able to stay in AL as function decreased, saw AL as home</p>	<p>Study was very extensive for a qualitative study, however limited by geography (one state).</p> <p>Issue of managing risk may be particularly key for development of policies related to decline in AL</p> <p>While not focused on EOL, natural progression from aging in place to terminal decline.</p>

Authors	Study Design	Sample Size & Type	Purpose of Study	Major Findings	Comments
(Cartwright & Kayser-Jones, 2003)	Longitudinal (over 6 months) grounded theory, using participant, observation, interviews and secondary materials	Four ALFs in a mixed rural-urban county in Oregon. Interviews with residents (n = 4), family members (n = 4), direct-care staff (n = 21). Hospice enrollment was not a requirement for participation, but all residents on study were enrolled in hospice.	Identify meanings participants attributed to their and other's situations during EOL	<p><i>Ageing in Place</i> not discussed</p> <p><i>Resident Characteristics</i> Frail, multiple chronic conditions, complex care needs, and multiple challenges related to providing end-of-life care.</p> <p><i>Challenges to EOL Care</i></p> <ul style="list-style-type: none"> • Inadequate staffing for EOL care needs • Lack of knowledge about EOL care • Esp. 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. <p>+ <i>Aspects of EOL in ALF</i></p> <ul style="list-style-type: none"> • ALF as home • Long-term, caring relationships between the resident and facility staff • Emotional and physical support from staff <p><i>Family Role</i> Hospice and family involvement may both be critical for end-of-life care in ALFs</p> <p><i>Staying in AL</i> seen as home, wanted to stay to death</p>	<p>Articulation of the potentially key role played by families</p> <p>Study was limited in size, scope and demographics (all white). Also, leaves open the question of how EOL care in ALFs happens when there is no hospice involvement</p>

Authors	Study Design	Sample Size & Type	Purpose of Study	Major Findings	Comments
(Dixon, Fortner, & Travis, 2002)	Focus groups (3)	Family n = 4 Admin of AL n = 6 Hospice team members n = 8	Clarify EOL issues in assisted-living communities	<p><i>Aging in Place</i> not discussed</p> <p><i>Resident Characteristics</i> not discussed</p> <p><i>Challenges to EOL Care</i></p> <ul style="list-style-type: none"> • 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 <p>+ <i>Aspects of EOL in ALF</i></p> <ul style="list-style-type: none"> • Sense of community • Care & attention from staff • Involvement of hospice <p><i>Family Role</i> not discussed</p> <p><i>Staying in AL</i> All three groups support right of aging in/dying in place & role of hospice to achieve goal</p>	<p>Study included only one hospice, one focus group of each type with very small numbers.</p> <p>Results very similar to Cartwright study.</p>

Authors	Study Design	Sample Size & Type	Purpose of Study	Major Findings	Comments
(Munn & Zimmerman, 2006)	Retrospective part of larger study (analysis of two open-ended questions) Constant comparative method, frequency of coded responses tracked Used structure /process/ outcome framework	Part of the <i>End-of-Life in Assisted Living and Nursing Homes</i> study which collected data on 792 deaths in stratified, random sample of 199 RC/AL facilities and 31 NH in 4 states 437 family members of individuals who died in RC/AL and NH	To establish the components of EOL care relevant in LTC according to family members based on responses and frequency of responses	<p><i>Aging in Place</i> not discussed</p> <p><i>Resident Characteristics</i> not discussed</p> <p><i>Challenges to EOL Care</i></p> <ul style="list-style-type: none"> • Staffing levels • Staff knowledge/ training • Staff turnover • Symptom management • Late/no referral to hospice <p>+ <i>Aspects of EOL in ALF</i></p> <ul style="list-style-type: none"> • Staff/resident relationships • Staff monitoring/care • Symptom management • Hospice care <p><i>Family Role</i></p> <ul style="list-style-type: none"> • Social support • Monitoring/advocate • Direct care • Desire to be there at time of death <p><i>Staying in AL</i> Would've liked to be able to bring home</p>	<p>Many similar conclusions to Cartwright & Kayser-Jones (2003) and Dixon et al. (2002)</p> <p>Major leaps made in conclusions (i.e. long discussion of "dignity" when not in data) No differentiation between NH and RC/AL Were able to fit comments into "Structure/Process/Outcome" framework, but wonder if it was truly a good fit?</p>

Table A2 Quantitative Research on Aging and End of Life in Assisted Living

Authors	Study Design	Sample Size & Type	Study Purpose	Measures Used	Variables Measured	Results	Comments
(Cartwright, Hickman, Perrin, & Tilden, 2006)	Cross-sectional, descriptive comparison Mixed methods Compared findings with those from prior studies	Family member most familiar with resident's death. 6 ALFs in a mixed urban-rural region of the PNW N = 25	Describe and compare the symptom experiences of AL residents during their final week of life. Compared with NH, private home and hospital. Also to describe family members' satisfaction with care at EOL	Modified Family Memorial Symptom Assessment Scale-Global Distress Index (FMSAS-GDI) Two closed questions regarding symptom management and quality of care Two open-ended questions regarding quality of care during last week of life.	Demographics of decedent; 7 physical symptoms (presence, frequency, level of distress it caused to decedent); 4 psychological symptoms (presence & frequency); overall level of comfort Satisfaction with symptom management Quality of care	<i>Aging in Place</i> not discussed <i>Resident Characteristics</i> Causes of death: <ul style="list-style-type: none"> • Dementia • Heart disease • Cancer • Pneumonia, • Renal failure, • "Old age" Symptoms <ul style="list-style-type: none"> • Lack of energy • Lack of appetite • Pain Symptom experience most comparable w/at-home deaths <i>Challenges to EOL Care</i> <ul style="list-style-type: none"> • Lack of EOL knowledge • Coordination of care • Communication 	Could low levels of symptom distress have to do with moving out the more complicated cases? Small sample, low response rate.

Authors	Study Design	Sample Size & Type	Study Purpose	Measures Used	Variables Measured	Results	Comments
						<p>+ Aspects of EOL in ALF Families felt most symptoms well managed, quality of care</p> <p>Family Role Not discussed</p> <p>Staying in AL Glad they could die at home.</p>	

Table A3 Qualitative Research on Family Caregivers in Long-Term Care

Authors	Study Design	Sample Size & Type	Purpose of Study	Major Findings	Comments
(Friedemann, Montgomery, Maiberger, & Smith, 1997)	Two part design: (a) a nursing home survey of family-oriented policies and practices (NH perspective (b) Interviews of family members (family perspective)	3-stage sampling: 24/143 NHs randomly selected from all Medicare/Medicaid licensed NHs in Detroit area that replied to survey. Family members of residents admitted over 22 months to these facilities invited n = 177	To investigate family involvement patterns, staff-family interactions, and nursing home factors that families perceive as helpful or inhibiting	<p>Family CG Activities/Roles</p> <ul style="list-style-type: none"> • Maintenance of family stability and connectedness • Maintenance of personality and dignity • Entertainment and general stimulation • Prevention of rapid decline. • Maintenance of [some of the] control of the caregiving situation • Monitoring of care provided by staff • Advocacy • Some CG activities • Some family members disengaged <p>Family Concerns</p> <ul style="list-style-type: none"> • Resident's health • Resident's well-being • Loss of identity • Quality of affective care • Facilities w/little family orientation—resident safety • Staff unwilling to engage with family • Physical plant <p>Family CG Motivation</p> <ul style="list-style-type: none"> • Maintenance of emotional bonds <p>FCG Emotional Response not discussed</p>	Study framed by Friedemann's system-based family theory. Was the data forced to fit the theory?

Authors	Study Design	Sample Size & Type	Purpose of Study	Major Findings	Comments
(Sanderson & Meyers, 2004)	Thematic & systematic comparisons	Family members of elderly resident who resided in ALFs in Southern California n = 16	<p>The emotional experience of CG when and after they decide to place CR in a LTC facility</p> <p><i>Three aims:</i> The emotional impact of caring for an elderly loved one How people decided to place family member How the CG managed after placing a loved one</p>	<p>Family CG Activities/Roles</p> <ul style="list-style-type: none"> • Visiting 1-several times/week • Helping w/ADLs/IADLs (bathing, dressing, laundry, medication administration, transport to dr. appointments) • Care continued after placement <p>Family Concerns not discussed</p> <p>Family CG Motivation</p> <ul style="list-style-type: none"> • Moral commitment • Fulfillment of expectations • Love • Reciprocity • family obligation • Some CG did not place until family or dr. ultimatum <p>FCG Emotional Responses</p> <p><i>During placement:</i></p> <ul style="list-style-type: none"> • Apprehension • Anger • Guilt • Relief • Happiness • Sadness • Overwhelmed <p><i>After placement:</i></p> <ul style="list-style-type: none"> • Guilt • Relief • Freedom • Reduction in worry • Continued commitment after placing • Same or greater closeness to CR 	<p>One of few studies that examines CG emotional response to situation</p> <p>Limited by being all middle to upper middle class</p>

Authors	Study Design	Sample Size & Type	Purpose of Study	Major Findings	Comments
(Wright, 2000)	Qualitative interviews Questions about attitudes, views, perceptions and experiences	UK Study 61 relatives of residents admitted during the preceding 3 years to 35 independent sector nursing or residential care homes	The roles that spouse and adult children FCG felt able to take with their loved one in a care home	<p>Family CG Activities/Roles Three major roles + 2 others:</p> <ul style="list-style-type: none"> • Checking the quality of care • Companionship • Handling the CR finances • Practical help • Personal care <p>Family Concerns</p> <ul style="list-style-type: none"> • Inadequate stimulation • Inadequate cleanliness • Perceived lack of respect for the cared-for person's dignity • Drugs – esp heavy sedation of PWD • Shortcoming usually attributed to staff shortages & turnover <p>Family CG motivation</p> <ul style="list-style-type: none"> • Love/affection • Obligation • Guilt <p>FCG Emotional Response Strong feelings involved w/visits</p> <ul style="list-style-type: none"> • love or affection • sense of obligation • Feeling of guilt for current situation • Increased closeness (children) • Lessened closeness (spouses) 	Don't know equivalence between British care home and US LTC settings

Table A4 Quantitative Studies on Family Caregiving in Long-Term Care

Authors	Study Design	Sample Size & Type	Study Purpose	Measures Used	Variables Measured	Results	Comments
(Gaugler & Kane, 2001)	<p>Longitudinal correlational secondary analysis</p> <p>Exploratory factor analysis to determine factor structure of informal help measure</p>	<p>38 of 39 licensed AL facilities in OR 6/95</p> <p>31/156 Medicare-certified NH in OR 1/3 AL residents; 2/5 NH residents randomly sampled</p> <p>This study sample: T1: AL n = 440; NH n = 156 T2: AL n = 325; NH n = 100 T3: AL n = 198; NH n = 82</p> <p>Cognitively intact</p>	<p>Study Questions: Do patterns of informal help differ between AL & NH residents at baseline, 6 months & 1 year?</p> <p>What are the determinants of informal help initially, over 6 months, & at 1 year for AL & NH residents?</p> <p>Hypothesis: factors and characteristics derived from the behavioral model will predict informal care use</p> <p>These include:</p> <ul style="list-style-type: none"> • Predisposing characteristics • Enabling factors • Need Characteristics 	<ul style="list-style-type: none"> • Questionnaires to staff on service utilization and residential hx. • AL admins interviewed at baseline on various facility characteristics <p>Measures:</p> <ul style="list-style-type: none"> • Dependent Variable: Residents asked if family or friend helped w/7 tasks (personal & instrumental help) • Expanded Behavioral Model • <i>Predisposing characteristics</i> • <i>Enabling characteristics:</i> • <i>Facility enabling characteristics:</i> <ul style="list-style-type: none"> ○ # of units ○ Metro/urban/rural 	<p><i>Predisposing characteristics:</i></p> <ul style="list-style-type: none"> • Age • Gender <p><i>Enabling characteristics</i></p> <ul style="list-style-type: none"> • Education • Marital status • # of children • If family w/i 1 hr drive • LOS • Location before moving to facility • ADLs/IADLs <p><i>Facility enabling characteristics:</i></p> <ul style="list-style-type: none"> • # of units • Metro/urban/rural 	<p>Family CG Activities/Roles</p> <ul style="list-style-type: none"> • AL residents received more instrumental assistance than NH residents—this did not change over time • Women received more informal help than men • Higher education levels = decreased help over time • Wider range of help from proximal relatives • Older and frailer received larger range of I & A help • Resident's positive perceptions of staff associated w/more types of informal help <p>Family Concerns not discussed (resident informant)</p>	<p>Secondary analysis not focused on informal help</p> <p>Not include intensity of effort</p> <p>Who source of specific help (who are CGs?)</p> <p>Data only from CR. Need data from CG</p> <p>Great for me it's Oregon, but generalizable?</p> <p>Suggests that AL setting is more conducive to informal help than NH</p>

Authors	Study Design	Sample Size & Type	Study Purpose	Measures Used	Variables Measured	Results	Comments
				<ul style="list-style-type: none"> • <i>Need characteristics</i> <ul style="list-style-type: none"> ○ Kahn-Goldfarb Mental Status Questionnaire ○ ADL dependencies ○ Self-assess general health ○ Psych well-being (SF-36) ○ Perceived quality of interactions w/AL staff 		<p>Family CG Motivation not discussed</p> <p>FCG Emotional Response not discussed</p>	
(Port et al., 2005)	<p>Cross-sectional, descriptive</p> <p>Structured interview w/select open-ended questions</p>	<p>Part of the <i>Dementia Care Project</i>, a study of individuals w/dementia living in 35 RC/AL facilities and 10 NH in 4 states</p>	<p>Information r/t family involvement of RC/AL residents w/dementia as compared to family members of NH residents w/dementia</p>	<p>No formal measures of CG</p> <p>Functional status of CR via MDS-ADL</p> <p>Comorbidities of resident by count of how many of 11 conditions had (physical & mental)</p> <p>Cognition of CR by MMSE and MDS-COGS</p>	<p>Sociodemographics (age, gender, race, kinship status, work status, education, income, number of dependents, months providing care, minutes to the facility), caregivers current health</p>	<p>Family CG Activities/Roles</p> <ul style="list-style-type: none"> • Involvement higher in RC/AL than NH CG • Medical monitoring • Financial monitoring • Monitoring of resident's wellbeing 	<p>Inclusion slightly tangential, but one of the few examples of examining actual FCG activities in AL.</p>

Authors	Study Design	Sample Size & Type	Study Purpose	Measures Used	Variables Measured	Results	Comments
		Stratified, randomized selection of residents, then contacted person most involved in care decisions for the resident n = 353			<p>Measured involvement by:</p> <ol style="list-style-type: none"> 1. Monthly out-of-pocket expenses spent toward resident care. 2. Time per week spent visiting or talking with the resident for primarily social reasons 3. Current self-rated involvement, self-rated (1-5 scale, high to low). 4. Preference for a different level of involvement 5. Level of burdened felt from caring for resident (0 -4) 6. Involvement in eight specific activities: 	<p>Family Concerns</p> <ul style="list-style-type: none"> • Responsiveness of staff • Continuity of care • Staffing ratios • Staff training/qualifications • Lack of openness with families about problems at facility • Communication <p>Family CG Motivation</p> <ul style="list-style-type: none"> • Maybe r/t willingness of AL to allow FCG involvement • Sense of responsibility <p>FCG Emotional Response</p> <ul style="list-style-type: none"> • Burden higher in RC/AL than NH • Feel need to be more involved 	<p>Impressive sample size, however problem with generalizability of typology</p> <p>No information re: how decided which activities to focus on.</p>

Authors	Study Design	Sample Size & Type	Study Purpose	Measures Used	Variables Measured	Results	Comments
(Ross, Carswell & Dalziel, 2001)	Descriptive exploratory design Questionnaires w/open-ended & fixed choice questions	Ottawa, Canada 9 LTC facilities family ID'd as involved w/ resident. <i>n</i> = 122	Investigate family caregiving in LTC.	Mostly questionnaire designed for study. Some modeled on/modified from earlier studies by author or other measures (FAMCARE)	Family visit frequency Family visit activities Reasons for visits Care-related activities carried out by family Satisfaction with formal care Care-related learning needs	<p>Family CG Activities/Roles</p> <ul style="list-style-type: none"> • Mostly indirect care • Advocate • Provide/organized/managed care • Personalized enviro • Emotional support • Within context of visiting <p>Family Concerns</p> <ul style="list-style-type: none"> • Being ignored by staff • CR pain Families want to know: <ul style="list-style-type: none"> • how to get most out of visiting • About the LTC system • Health status changes • How to deal with behavioral issues r/t CI • How to best interact w/staff 	Good illustration of the level of involvement of FCG that goes beyond just counting frequency

Authors	Study Design	Sample Size & Type	Study Purpose	Measures Used	Variables Measured	Results	Comments
						<p><i>Family CG Motivation</i></p> <ul style="list-style-type: none"> • Maintain emotional bonds • Continuity of family relationships • Obligation & commitment • Ability to monitor care <p><i>FCG Emotional Response</i></p> <ul style="list-style-type: none"> • Didn't know how to "visit" • Unprepared for intensity of care provide after placement • Committed to remain involved and participate in care 	

Table A5 Qualitative Studies on End of Life in Long-Term Care

Authors	Study Design	Sample Size & Type	Purpose of Study	Major Findings	Comments
(Goodridge, Bond, Cameron, & McKean, 2005)	Retrospective, exploratory, descriptive, interviews	Individuals involved w/the deaths of 15 residents of the “Personal Care Home” part of a LTC facility in Winnipeg, Manitoba. Total participants $n = 26$ 14 RNs 8 Healthcare aides 4 Family members	To gain an understanding of the perspectives of FMs, RNs and HCAs regarding the last 72 hours of NH residents lives, with a goal of identifying the commonalities of views	<p>Resident Characteristics</p> <ul style="list-style-type: none"> • Pain documented for 33.3% of residents • Analgesics administered to 66.6% residents • Pain and dyspnea most distressing problem in the last 72 hours of life • Dyspnea occurred in almost all the dying residents and was a much more common symptom than pain <p>Challenges to EOL Care</p> <ul style="list-style-type: none"> • Coordination of care (between family, staff & team) • Awareness of how much information family is able to cope with • Difficulties of watching a protracted death • Fear of resident dying alone <p>+ Aspects of EOL in LTC</p> <ul style="list-style-type: none"> • Staff caring behaviors: emotional support of both resident & family seen as key • Relationships of staff with resident/families • Education of family esp about symptoms of dying, what to expect after death 	<p>Interesting study for use of different groups</p> <p>Almost no negative experiences reported – selection bias?</p>

Authors	Study Design	Sample Size & Type	Purpose of Study	Major Findings	Comments
(Hanson & Henderson, 2000)	Focus groups	<p>Participants from two NH: one for profit free-standing part of national chain, other local, non-profit part of CCRC</p> <ul style="list-style-type: none"> • 11 focus groups • four groups for nurses (RN and LPN), • four groups for nursing assistants • three groups for physicians. • Groups ranged in size from three to 13, • Total n = 77 	<p>To define a good dying experience in a LTC facility</p> <p>To describe factors that promote or prevent good care for the dying in this setting.</p>	<ul style="list-style-type: none"> • Environmental support • Emotional support • Smooth transition of focus of care <p>Family Role</p> <ul style="list-style-type: none"> • Some families wanted to remain with or provide care for dying resident • Recognition of ambivalence r/t death <p>Resident Characteristics None described</p> <p>Challenges to EOL Care</p> <ul style="list-style-type: none"> • Characteristics of the LTC setting influence the dying experience. • Bad deaths characterized by: <ul style="list-style-type: none"> ○ Prolonged and severe physical suffering ○ Extreme fear and anxiety ○ Loss of dignity • Lack of resources • the intensity of regulation and paperwork, • the burden of a negative public image. <p>+ Aspects of EOL in LTC</p> <ul style="list-style-type: none"> • Believed most of the LTC deaths experienced were good deaths 	<p>Good to have range of participants</p> <p>Some of the focus groups were small</p> <p>Perception of no family involvement surprising and not in keeping with other studies</p>

Authors	Study Design	Sample Size & Type	Purpose of Study	Major Findings	Comments
				<ul style="list-style-type: none"> • Leadership of nurses • Nurse's and CNAs able to recognize approaching death secondary to changes in function & behavior • Key characteristics of good deaths: <ul style="list-style-type: none"> ○ Appropriate ethical decision making ○ Good symptom management ○ Emotional and spiritual preparation 	
				<p>Family Role</p> <ul style="list-style-type: none"> • Did not describe much/any family involvement: families often lived out of town, were emotionally distant, or simply did not feel comfortable in the LTC environment • Nurses and CNAs believed they became surrogate family to some dying residents • Dependence on nurses' assessment skills and ability to provide first communication with families about death and dying issues 	

Table A6 Quantitative Studies on End of Life in Long-Term Care

Authors	Study Design	Sample Size & Type	Study Purpose	Measures Used	Variables Measured	Results	Comments
(Baer & Hanson, 2000)	Retrospective, cross-sectional descriptive	North Carolina NH hospice enrollees who died between 12/97 – 5/98 Eligible sample of 398 family members response rate 73% N = 292	Do surviving family members of enrollees perceive benefit from hospice for dying NH residents?	Survey created for the study: 25 multiple choice, & 3 open-ended questions Open-ended questions: any other uncomfortable symptom present during the last 3 months of life special services provided by hospice and/or NH	Physical symptoms: (pain & dyspnea, frequency and severity (on a typical day) Emotional or spiritual symptoms (depression, anxiety, loneliness & readiness for death) severity on a typical day Open-ended questions: any other uncomfortable symptom present during the last 3 months of life special services provided by hospice and/or NH	Resident Characteristics <ul style="list-style-type: none"> • Pain, constipation & shortness of breath were active problems ranging from mild to severe • 70% experienced feeding problems. • 80% of the subjects had severe urinary incontinence (almost 50% no skin problems) Challenges to EOL Care <ul style="list-style-type: none"> • 28% did not think resident had a good death • Symptoms not well controlled • Family not notified when death is near 	Older data, limited to one state Use of “typical day” as time measure creates a highly subjective measure

Authors	Study Design	Sample Size & Type	Study Purpose	Measures Used	Variables Measured	Results	Comments
						<ul style="list-style-type: none"> • Families not aware of changes during dying process • Need to deal w/emotional ambivalence about placement 	
						<p>+ Aspects of EOL in LTC</p>	
						<ul style="list-style-type: none"> • NH/Hospice made it possible to die w/dignity • Significant improvement in the quality of care for physical and emotional symptoms after hospice. • Hospice care allowed residents to avoid hospitalization while dying • Hospice and NH services unique—no duplication • NH worked to provide private room for resident & family 	

Authors	Study Design	Sample Size & Type	Study Purpose	Measures Used	Variables Measured	Results	Comments
(Bosek, Lowry, Lindeman Burck, & Gwyther, 2003)	Mixed methods Survey with short additional short-answers	57 family members of persons w/AD who had died while residents of a national nursing home chain Sample from national study of EOL care for PWD	What is the experience of dying from AD in a NH, as described from the perspective of the primary family caregiver.	Structured telephone interview concerning the healthcare decisions made during the last 3 days of the AD patient's life	How the NH/hospice helped person die w/dignity Rating of a "good death." Reasons why did/didn't experience a good death	<p>Family Role</p> <ul style="list-style-type: none"> • Nothing explicit – families stated death was "painful to watch" • 68% not present at time of death <p>Resident Characteristics Residents w/AD, otherwise not discussed</p> <p>Challenges to EOL Care</p> <ul style="list-style-type: none"> • Almost 1/3 thought did not have a good death • Negative physical and emotional experiences: pain, bowel issues, dyspnea, immobility, scared • Difficult for family to watch 	Focus on last 3 days of life very limiting Uses a very specific model for "good death" not shared w/ participants

Authors	Study Design	Sample Size & Type	Study Purpose	Measures Used	Variables Measured	Results	Comments
						<ul style="list-style-type: none"> • 28% of family members did not believe that a good death could occur when the person is dying from Alzheimer's disease or dying in a nursing facility • Not contacted when resident dying <p>+ Aspects of EOL in LTC</p> <ul style="list-style-type: none"> • 89% thought NH/hospice helped PWD die with dignity • Considered a good death when family was present, time to say goodbye, quick death, expected death <p>Family Role 68% not present at death. No other comments about family activity</p>	

Authors	Study Design	Sample Size & Type	Study Purpose	Measures Used	Variables Measured	Results	Comments
(Travis et al., 2002)	Retrospective chart review Used both qualitative and quantitative methods of data collection	41 all NH residents within a private, nonprofit CCRC in SW US who died in the 18-month period 1/98 to 6/99	Using the framework of 4 EOL care obstacles, examining how EOL unfolds in LTC	Operationalized 4 obstacles: <ul style="list-style-type: none"> • Failure to Address Treatment Futility • Lack of Communication Among Decision Makers • No Agreement on a Course for End-of-Life Care • Failure to Implement a Timely End-of-life Plan of Care 	Frequencies of each of the four obstacles Evidence of a hierarchy of obstacles Associations of obstacles and background variables including: <ul style="list-style-type: none"> • resident's age • mental functioning, • length of stay in the nursing facility • hospitalization history in the last year of life 	Resident Characteristics not discussed Challenges to EOL Care 4 Obstacles to EOL care <ul style="list-style-type: none"> • Failure to recognize treatment futility • Lack of communication among decision makers • No agreement on a course for end-of-life care • Failure to implement a timely end-of-life plan of care. • Hospitalization in the last year of life related to more obstacles of care • Short hospice stays, particularly after hospitalization 	Limited examination of obstacles to the 4 developed How is this setting different (CCRC, most residents of the NH had been long-time residents of the community) Limitations of using only medical records

Authors	Study Design	Sample Size & Type	Study Purpose	Measures Used	Variables Measured	Results	Comments
						<ul style="list-style-type: none"> • Clinicians reluctant to state tx futility b/c of rehab climate + Aspects of EOL in LTC • 46% of the cases had no obstacles to their palliative and EOL care Family Role Families vary widely in their receptivity to communications about conflicting opinions about care and treatment decisions 	

Appendix B

Interview Guide, Observation Guide, and Demographic Forms

Interview Guide

I am interested in understanding what it is like to be helping [AL resident] now that she is living in assisted living and on hospice. I'm going to start by ask you some background questions to get a general idea about who you and [AL resident] are, then I'll ask some questions to help me understand better what it has been like having [AL resident] at [AL residence]. After that I'd like to talk about what has been like having hospice involved with [AL resident's care].

1. To start, would you tell me the process that led to [AL resident] living at [AL residence]?

Probes:

- a. How/why was the decision made for [AL resident] to live there?
 - i. Why AL instead of another setting?
 - b. Where was [AL resident] living before?
 - c. Who was involved in choosing a place for [AL resident] to live?
 - d. Was your hope that this would be the last move [AL resident] would have to make?
 - e. What were your expectations of how the AL would help [AL resident]?
 - f. Your expectations of what would change/stay the same between you and [AL resident]?
2. I'd like to learn what it is like for families when a family member is living in AL and also receiving hospice services. Could you start by telling me about your Mom's current illness — when you realized she was ill, [her condition was getting worse to the point], and that hospice services were needed.
 3. Tell me about what it is like having [AL resident] on hospice here at [AL residence] now.
 4. What do you see as your role in caring for [AL resident] now?

Probes:

 - a. What types of things are you doing with [AL resident]?
 - b. What types of things are you doing with hospice?
 - c. What types of things are you doing with [AL]?
 - d. How does it feel to be doing these things?

5. What is the role of hospice in [AL resident's] care?
 - a. Who is providing care?
 - b. What types of activities/services do they provide?
 - c. How is hospice meeting your expectations regarding how they would care for your [AL resident]?
 - d. Is there anything that you wish they would do differently in caring for your Mom?

6. What is the role of AL in your [AL resident's] care?
 - a. Who is providing care?
 - b. What types of activities/services do they provide?
 - c. How is the AL meeting your expectations regarding how they care for [AL resident]

7. What about other family members—how are they involved in [AL resident's] care?
 - a. What types of activities are they doing?
 - b. Is there anything that you wish they would do differently in caring for [AL resident]?

8. How are things changing in terms of who is doing what types of care with [AL resident]?

PROBE: Tell me about this (if yes, there have been changes in how the care is managed)

9. How are your expectations regarding care being met by hospice & AL?

10. What is particularly challenging about caring for [AL resident] now?
 - a. What concerns do you have about [AL resident's] care now and in the future?
 - b. Any challenges specific to [AL resident] living at [AL facility]?

11. What is particularly rewarding?

12. What kind of changes have you had to make in your personal life to provide this care?

Probes:

 - a. Job?
 - b. Economic hardship?
 - c. Changes in relationship?

13. How is this experience affecting you?

14. If you could change anything about this process ([AL resident's] end-of-life experience, your experience in caring for [AL resident] at end-of-life), what would you change?

15. Is there anything else you would like to share with me at this time?

Observation Guide

1. The resident's private space:
 - a. Size? (studio, one bedroom, etc.)
 - b. How personalized is the space?
 - i. Are there pictures of family members, animals, etc
 - ii. Other personalizing touches
 - iii. Fresh flowers or house plants?
 - iv. Spiritual symbols?
 - c. Room temperature?
 - d. Are there comfortable places to sit?
 - e. Has a hospital bed been moved in?
 - f. Other hospital or medical equipment? (OTBT, oxygen, etc)
 - g. How is the resident oriented in the room? (able to look out a window, in a corner, in eyesight of the door)
 - h. Is the space generally neat and tidy, or does it feel chaotic, crowded, messy?
 - i. Are there any odors?
 - j. Is the door open or closed?
 - k. If there is a separate bedroom, where is the resident? Is the door open or closed?
 - l. What does the bathroom look like? Can it be used or has it become a storeroom?
 - m. Aural ambiance? (music, TV, O2 concentrator,) pleasant or noisy?
 - i. Who chose the music/TV channel?
 - n. Are there any pets?
 - o. What do the windows look out on?
 - i. Are the curtains/blinds open/closed?
2. Resident/family member (FM) interactions:
 - a. What does the FM call the resident?
 - b. What does the resident call FM?
 - c. How do they greet each other?/talk to each other?
 - d. Where does the FM sit in relation to the resident?
 - e. Do interactions appear comfortable? Strained? Tense? Nervous?
 - f. Are there other family or visitors?
 - g. Is the FM on the phone a lot?
 - h. Does the FM have "projects" or other things to occupy them?

- i. How does care unfold? In response to requests, spontaneous, asked if wanted?
3. AL Staff/resident/FM interactions:
 - a. Who comes into the room?
 - b. Do they knock first?
 - c. How do they greet/interact with the resident?
 - d. Do they appear to know the resident?
 - i. Are there any signs of affection exchanged? (endearments, hugs, etc)
 - ii. Do they seem comfortable with the resident?
 - e. How do they greet/acknowledge the FM?
 - f. What do they do while they are in the room?
 - g. What kind of comments (if any) are made about the staff person(s) by the resident and/or FM?
 4. Hospice staff/resident/FM interactions:
 - a. Who from hospice is present?
 - b. What are the interactions between the hospice staff member and the resident like?
 - c. What are the interactions between the hospice staff member and the FM like?
 - i. Is there any teaching/coaching/education occurring?
 - ii. Is this a regular hospice staff or someone covering?
 - iii. What is the feeling of the interactions? Warm? Distant?
 - d. What kind of comments (if any) are made about the hospice staff person(s) by the resident and/or FM?
 5. What is the AL as a general space like?
 - a. Is the building old/new?
 - b. Odors, sounds/sound level?
 - c. Any spiritual symbols?
 - d. Is there someone at a front desk?
 - i. Is everyone who comes in acknowledged?
 - ii. Do people have to sign in?
 - e. Does it feel welcoming or maze-like/confusing?
 - f. How is the public space? Is it comfortable? Homey? Stiff?
 - i. Are there plants (live or artificial?), animals, etc.
 - ii. Is there more than one gathering area?

- iii. Are the outside areas welcoming?
- iv. Are people in the common space?
 - 1. Are they interacting with each other?
 - 2. With staff?
 - 3. Is there much sign of staff around?
 - 4. Does it feel lively? Crowded? Tomb-like?
- v. Are there garden areas?
 - 1. If the weather is nice, is anyone in them?
- g. Is it clear where the med room is? Where the nurse is?
 - i. Is there some kind of clear “nurses station?”

Demographic Data: Participant Data

Age: _____

Gender: F M

Relationship to AL Resident

Employment Status:

Employed FT Employed PT Not employed outside the home

Other _____

Marital Status: _____

Family Status:

No other dependents Other dependents (describe)

Highest grade completed? _____

Number of individuals in household: _____

Experience as a caregiver _____

Past experience with hospice

Distance to AL from home _____

Frequency and duration of visits _____

Which of the following four statements describes your ability to get along on your income?

1. I can't make ends meet
2. I have just enough, no more
3. I have enough with a little extra sometimes
4. I always have money left over

Which category represents the total amount of your yearly household income?

Under \$10,000	\$10,000-\$19,999	\$20,000-\$34,999
\$35,000-59,999	\$60,000-\$99,999	\$100,000 or more

Demographic Data: Assisted Living Resident Data

Age: _____

Gender: F M

Terminal
diagnosis: _____

LOS in Hospice _____

Length of residency in AL facility: _____

Private Pay or Medicaid?

Appendix C

Consent Form for Human Research



Oregon Health & Science University
Consent & Authorization Form

IRB#: 4997

Protocol Approval Date: 03/04/2009

OREGON HEALTH & SCIENCE UNIVERSITY
Consent & Authorization Form

TITLE: *The Experiences of Family Caregivers of Assisted Living Residents Enrolled in Hospice*

PRINCIPAL INVESTIGATOR: Theresa A. Harvath, PhD, RN, CNS
(503) 494-3855

CO-INVESTIGATORS: Miriam A. E. Volpin, BS, RN-CHPN, Doctoral
Candidate (971) 678-2908

SPONSOR: There is no sponsor for this study.

This form contains important information about the study in which you are being invited to participate. Please read the form carefully, ask questions of the investigators or others who are obtaining your consent to participate in the study, and take time to think about your participation. You may want to discuss the study with your family or friends before agreeing to be in the study.

What is the purpose of this study?

You have been invited to be in this research study because you are a family member or close friend of someone who lives in an assisted living facility (ALF) and who is enrolled in hospice. The purpose of this study is to find out more about what it is like to be involved in the care of someone who is very ill and living in an assisted living facility (ALF). A total of 15 to 20 family members of assisted living residents enrolled in hospice will be enrolled into the study.

What is required to participate in this study?

To qualify for this study, you must meet the following criteria:

1. You must be family or a close friend of someone who lives in an assisted living facility who is enrolled in hospice, and who spends time with the assisted living resident.
2. You must be over 18 years old.
3. You must speak English.

What can I expect as a study participant?

This study has two parts, an interview and observations. First, the investigator will interview you for about 30 to 90 minutes. The interview will be done privately at a time and place that is convenient for you. You will be asked to talk about the things you do for your family member/friend, as well as what helps you to do this and what makes it more challenging. This interview will be audio recorded.

At the time of the interview, the investigator will invite you to participate in the observation portion of the study. If you would like to participate, once or twice a week, when you are visiting your friend or family member at the assisted living facility, the investigator will spend time observing some of the things you do to help care for him or her, as well as your interactions with assisted living and hospice staff, if they are present. These observations are expected to last 30 minutes to 2 hours. The number and duration of visits will be negotiated with you.

If you have any questions regarding this study now or in the future, contact Miriam Volpin at (971) 678-2908.

What effect will this study have on my care?

Being in this study will not affect any care that you might receive at OHSU. It will not affect the care that your family member/friend receives at the ALF or from hospice.

How will my privacy be protected?

We will protect your privacy in the following ways:

1. Your name or other protected information will not be used. Instead, we will identify you by a code number. Observation and interview information is coded.
2. Information stored in a computer will have a restricted password. Written notes will be kept in a locked file cabinet. Transcriptions of interviews will be identified by a code number and all identifying information will be deleted.
3. Only the researchers involved with this study will have access to your information. All data obtained will be used specifically for research purposes.
4. All recordings and notes will be destroyed after analysis has been completed.

The persons who are authorized to use and/or disclose your health information are all of the investigators who are listed on page one of this form and the OHSU Institutional Review Board.

The persons who are authorized to receive this information are the Office for Human Research Protections as required for their research oversight and public health reporting in connection with this research study.

This authorization will expire and we will no longer keep information that we collect from you five years after all the analysis is completed.

Under Oregon Law, suspected child or elder abuse must be reported to appropriate authorities.

What are the possible risks of participating in this study?

Although we have made every effort to protect your identity, there is a minimal risk of loss of confidentiality. Some of the questions may seem very personal and deal with private or sensitive issues. These questions may cause you to become emotionally upset. You may stop the interview and/or observation at anytime. If you would like to talk to someone about these feelings, an appropriate referral for counseling will be made.

What are the possible benefits of participating in the study?

You may or may not personally benefit from being in this study. Some people find it helpful to talk about their experiences that may be difficult to share with others. By serving as a study participant, you may help us learn new information that could benefit patients, their families, and health care providers in the future.

Will it cost anything to participate?

There are no costs to you for participating in this study. No reimbursement or compensation will be given you as a result of your participation in this study.

What if I am harmed or injured in this study?

If you believe you have been injured or harmed while participating in this research and require immediate treatment, contact Terri Harvath at (503) 494-3855 or Miriam Volpin at (971) 678-2908.

You have not waived your legal rights by signing this form. If you are harmed by the study procedures, you will be treated. Oregon Health & Science University does not offer to pay for the cost of the treatment. Any claim you make against Oregon Health & Science University may be limited by the Oregon Tort Claims Act (ORS 30.260 through 30.300). If you have questions on this subject, please call the OHSU Research Integrity Office at (503) 494-7887.

What are my rights as a participant?

If you have any questions regarding your rights as a research subject, you may contact the OHSU Research Integrity Office at (503) 494-7887.

You do not have to join this or any research study. If you do join, and later change your mind, you may quit at any time. If you refuse to join or withdraw early from the study, there will be no penalty or loss of any benefits to which you are otherwise entitled.

You have the right to revoke this authorization and can withdraw your permission for us to use your information for this research by sending a written request to the Principal Investigator listed on page one of this form. If you do send a letter to the Principal Investigator, the use and disclosure of your protected health information will stop as of

the date she receives your request. However, the Principal Investigator is allowed to use information collected before the date of the letter or collected in good faith before your letter arrives. Revoking this authorization will not affect your health care or your relationship with OHSU

If the researchers publish the results of this research, they will do so in a way that does not identify you unless you allow this in writing.

You may be withdrawn from the study if the investigator stops the study.

To participate in this study, you must read and sign this consent and authorization form. If you withdraw your authorization for us to use and disclose your information as described above, you will be withdrawn from the study.

We will give you a copy of this form.

SIGNATURES:

Your signature below indicates that you have read this entire form and that you agree to be in this study.

Signature of Participant
Date

Signature of Investigator
Date

Printed Name

<p style="text-align: center;">OREGON HEALTH & SCIENCE UNIVERSITY</p> <p style="text-align: center;"><i>INSTITUTIONAL REVIEW BOARD</i></p> <p style="text-align: center;"><i>PHONE NUMBER (503) 494-7887</i></p> <p style="text-align: center;">CONSENT/AUTHORIZATION FORM APPROVAL DATE</p> <div style="border: 1px solid blue; padding: 5px; text-align: center; margin: 10px auto; width: 150px;"> <p style="color: red; font-weight: bold; font-size: 1.2em;">Mar. 4, 2009</p> </div> <p style="text-align: center;">Do not sign this form after the Expiration date of: <u>03/03/2010</u></p>

Appendix D

Trajectory of FCG Involvement:
Visual Portrayal of the Intensity of Family Caregiving

Trajectory of FCG Involvement:

Visual Portrayal of the Intensity of Family Caregiving

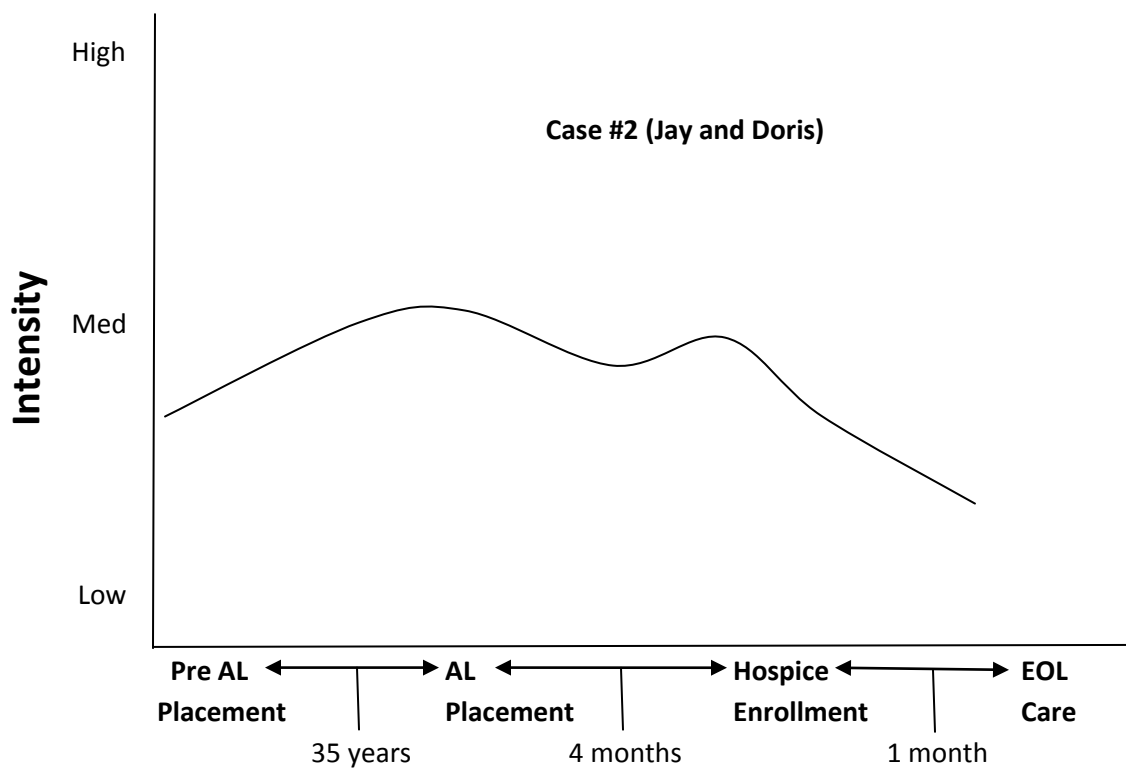
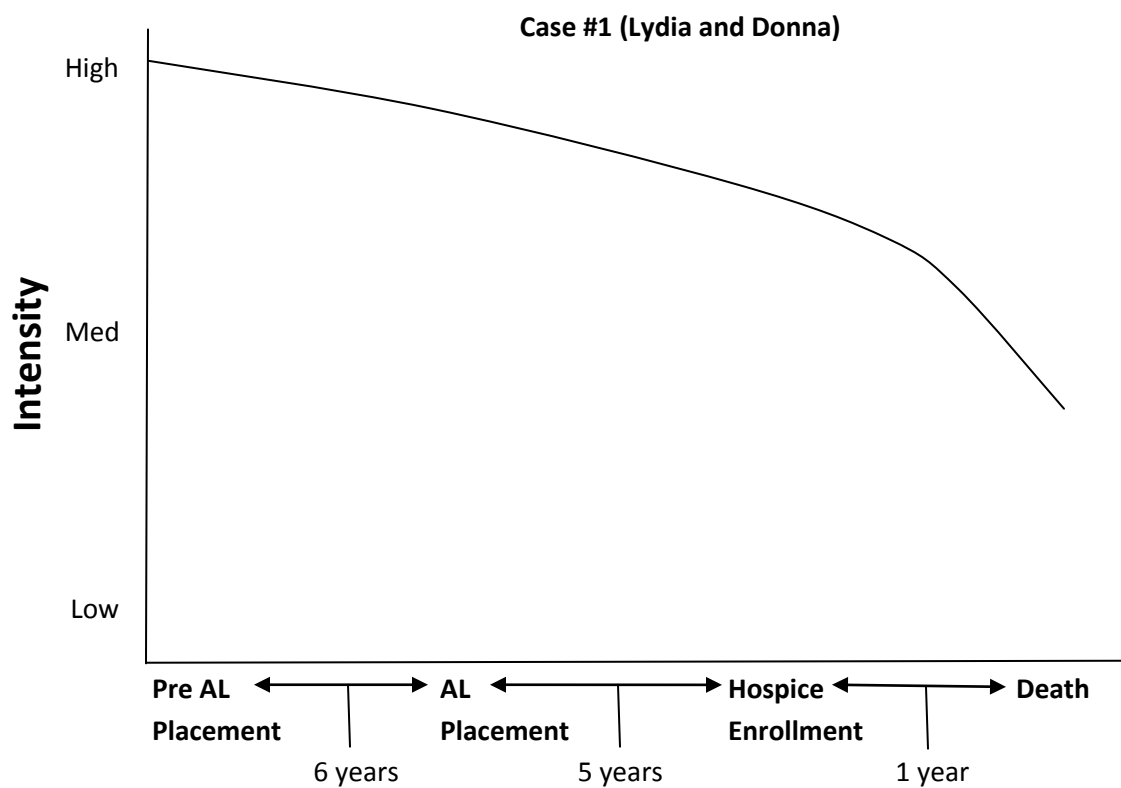
In an effort to capture changes in family caregiver (FCG) activities over time, the level of intensity of involvement was analyzed. In order to create a graphical representation of caregiving intensity, this caregiving intensity was labeled “low,” “medium,” or “high,” based on the following criteria.

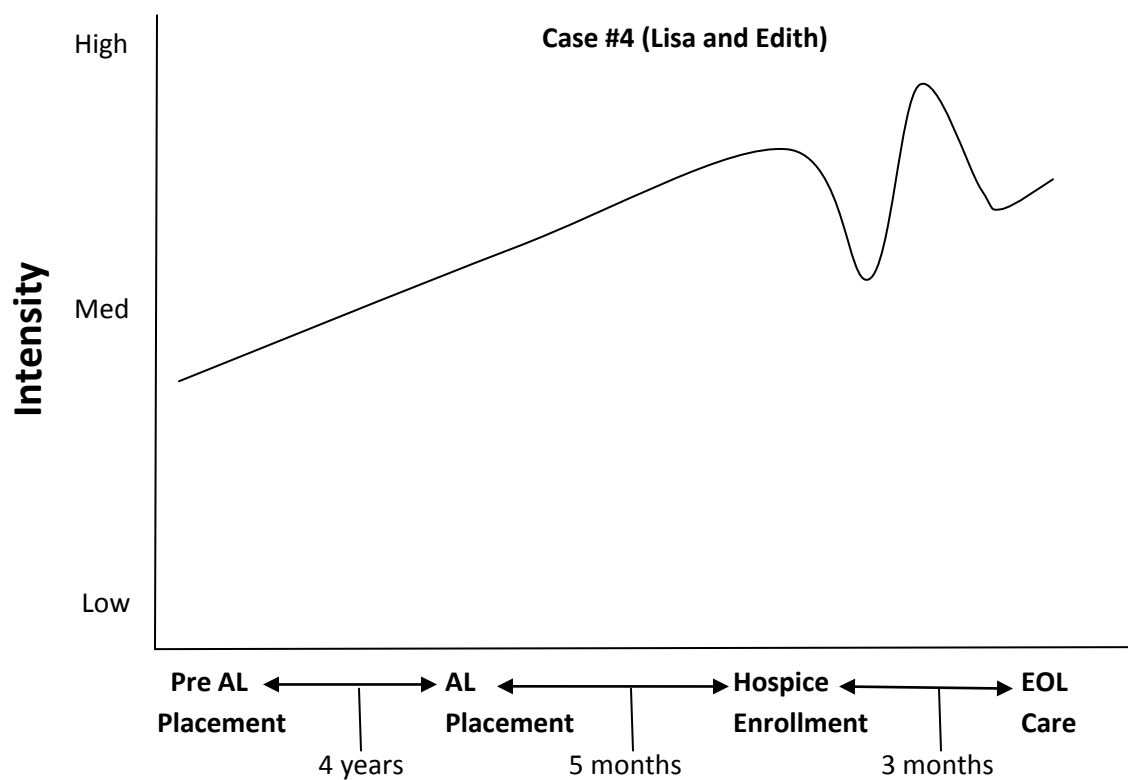
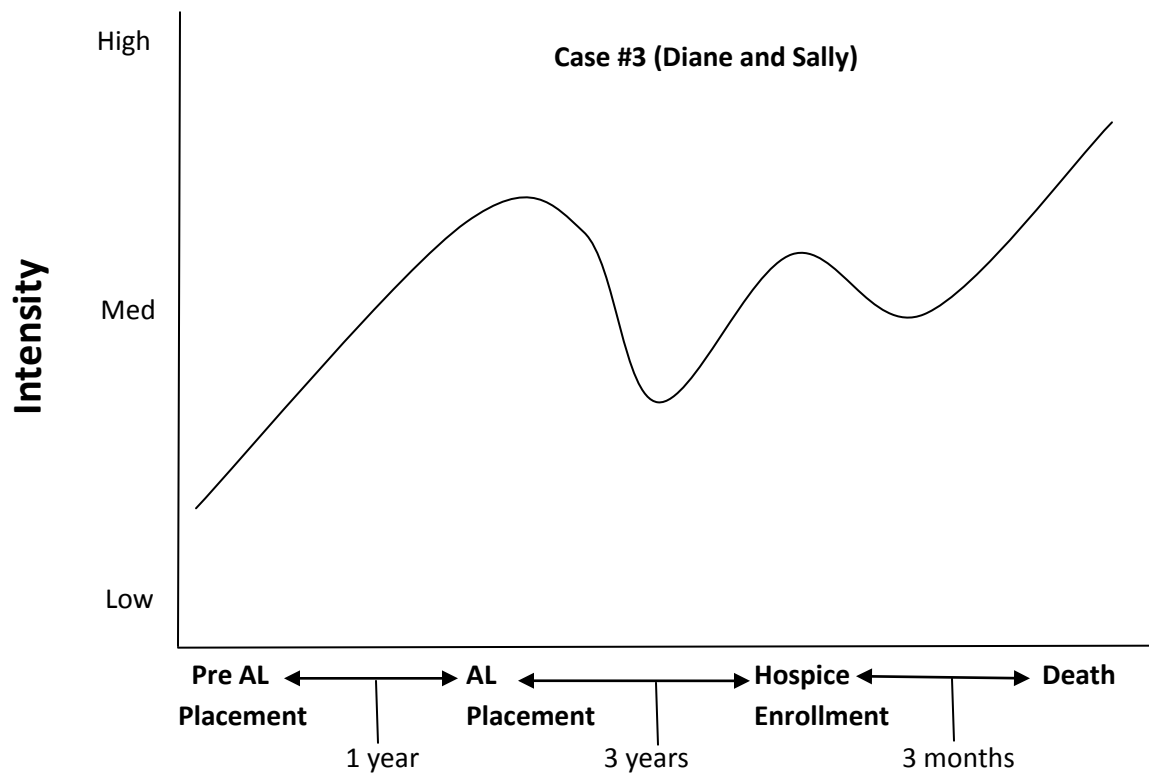
Low Intensity: Caregiving is fairly limited and “hands off.” Caregiving has a social focus. Visits are up to three times a week and are generally short. Oversight of the assisted living (AL) facility and/or hospice is limited. There is no attempt or desire for contact with the hospice RN (HRN) other than that initiated by the HRN. The FCG may feel that their presence has limited impact on the care recipient (CR)’s care or quality of life.

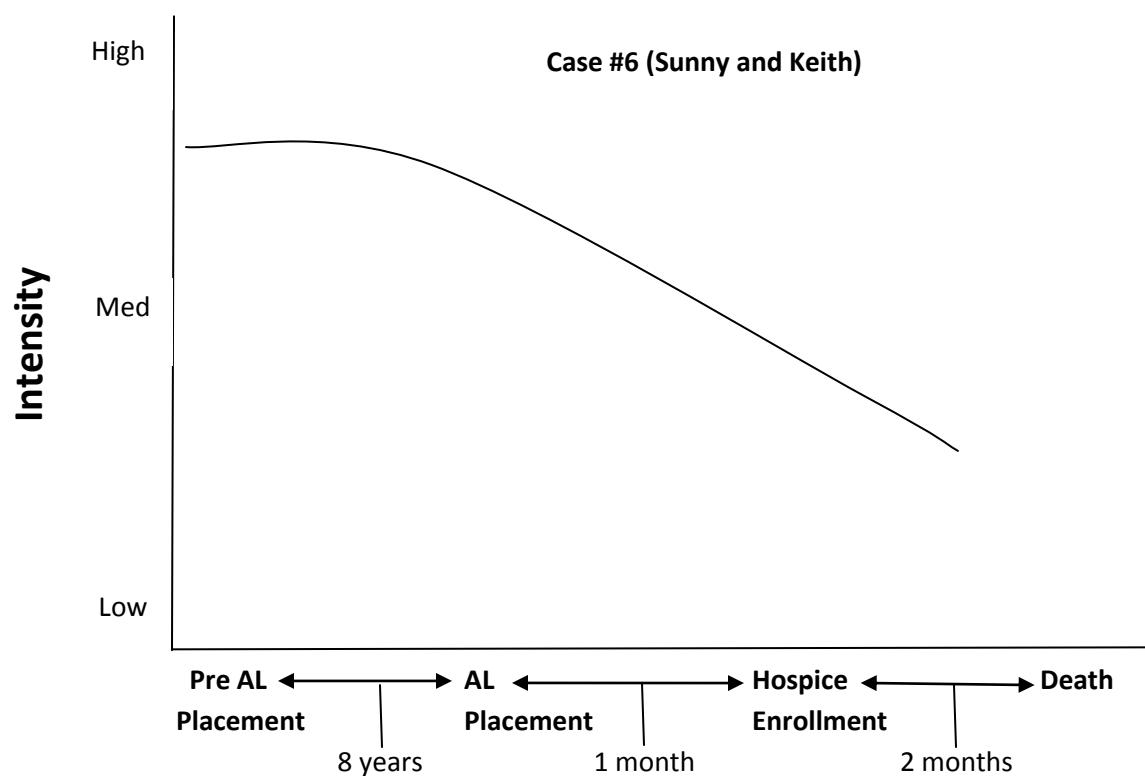
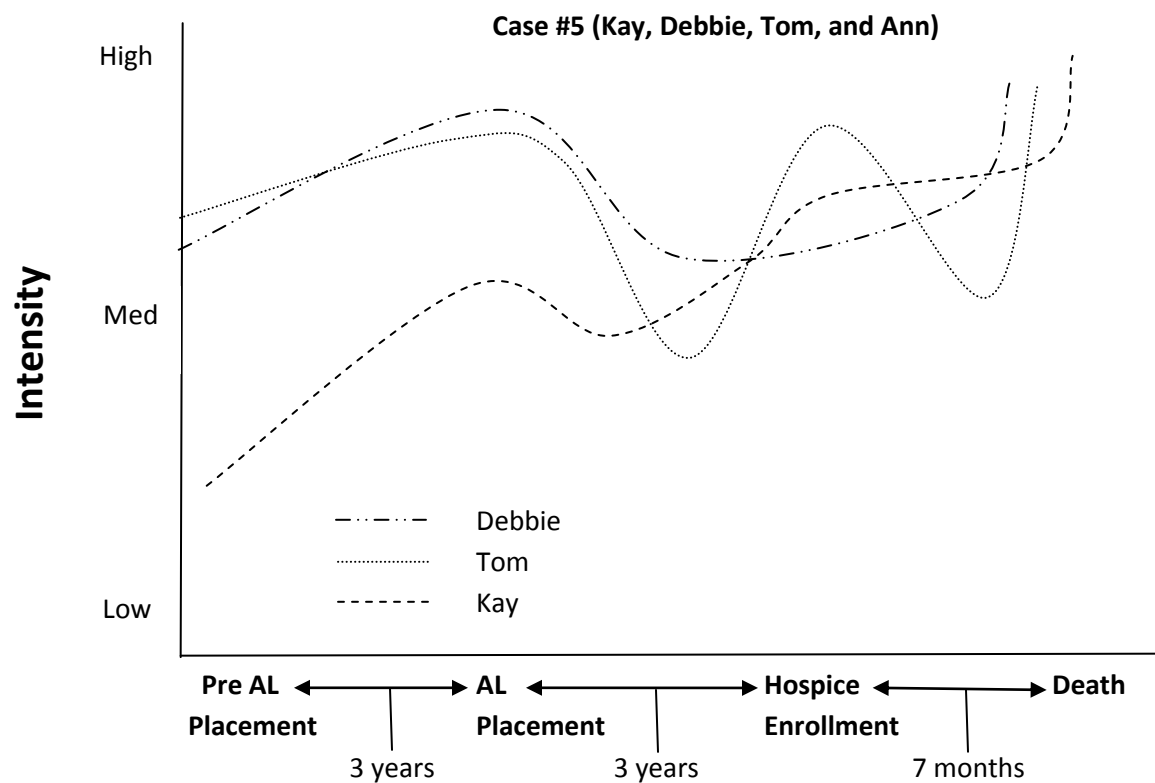
Medium Intensity: Caregiving activities appear to occur more often (3–5 times a week) and are more varied. Besides social aspects there are more activities related to meeting not just the CR’s needs but also their desires. Caregivers are much more likely to be directly engaged with AL facility and/or hospice staff, providing them with feedback, suggestions, and requests. There is some oversight and monitoring of care; however, the FCG is not as directive with care as is the case with high intensity caregiving.

High Intensity: Family caregivers are present every day or almost every day, often spending several hours with the care recipient. FCGs appear to be highly involved with the provision of care, either by directing care, overseeing care, or providing personal care.

The following graphs represent the caregiving activities of the ten participants in this study. Participants providing care for the same care recipient were put on the same graph.







Case #7 (Ileana, Reisa and Sasha)

