

Assisted Living Homes and the Dementia Caregiver: Do Assisted Living Home
Visitation Recommendations Matter?

By

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ABSTRACT

Title: Assisted Living Homes and the Dementia Caregiver: Do Assisted Living Home Visitation Recommendations Matter?

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Someone in the United States develops Alzheimer's disease every 68 seconds; by 2050 it will be every 33 seconds (Alzheimer's Association, 2013b). Nationwide caregivers provide 80% of the care given in the community (Institute of Medicine, 2008). Dementia is increasingly cited as a reason for long-term care. In 2010, forty-two percent of residents in assisted living had Alzheimer's disease or other related dementias (Polzer, 2013). When family caregivers (FCGs) are no longer able to provide the care required, transitioning into AL or other long-term care environment is often necessary.

This dissertation used a qualitative descriptive approach to examine how the AL's approach to visitation between the FCG and the PWD influenced the admission transition for the FCG. The specific aims were to 1) describe the FCGs' experience when a PWD transitions to AL; and 2) describe how the FCGs understanding of visitation recommendations of the AL (encouraged, neither encouraged nor discouraged, discouraged) influenced the FCGs' perceptions of and reactions to the admission transition.

This study identified the driving force behind the family caregivers' (FCGs) decision to transition a person with dementia (PWD) to assisted living (AL) was

the safety of the PWD or the people around them. For FCGs providing care in their own home this was often coupled with exhaustion. For most of the FCGs in this study, the upheaval associated with the transition never really subsided, even years after the initial move. They did not follow a linear progression, but instead vacillated between the overwhelmed phase, the adjustment phase, and initial acceptance (Brooke, 1988; S. A. Wilson, 1997). The ability to transition appeared to be predicated on the ability of the PWD to complete the adjustment phase and achieve initial acceptance. This offers an opportunity to re-conceptualize transition as a dynamic interdependent process and shift the focus of care from an individual patient centered approach to one that is family centered. Not only does this finding have theoretical and clinical implications, but also implications for research. By limiting investigation to those who are only 6-12 months out from the move, researchers may be missing important information that will expand our understanding of this phenomenon.

Each act of caregiving performed by the FCG in this study was a way to stay connected to the PWD, of not forgetting the PWD as the disease progressed. Interventions studies are needed to examine the extent to which connection supports the transition process.

This study extended our understanding by identifying fear as a strong motivator for visitation. The greater the fears, the more often FCGs visited. The effect of fear on the frequency of visitation and the ability of FCGs to find balance suggests that nursing and AL staff may play an integral role in providing

guidance and assurances that the PWD will receive the care and support they need.

In this study FCGs were allowed to come and go as they pleased. FCGs perceived this approach as helpful, if not physically taxing. ALs frequently contacted the FCGs to assist with calming the PWD when the PWD became agitated. It is unknown whether this was motivated by concern for the PWD or to reduce staffing needs. Regardless of the reason, the FCGs found the openness of the visitation schedule comforting. However, without guidance from the AL staff, FCGs may inadvertently prolong the time for transitioning for the PWD.

Expansion of our understanding of this process may provide knowledge that could be utilized to develop and test interventions to best support FCGs, PWDs, and AL staff. Not enough is known about the phenomenon suggesting further qualitative investigation is needed. Additionally, before quantitative studies can be performed that evaluate the impact of fear on visitation the development of a valid and reliable measure needs to occur.

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Chapter 1: Introduction

Statement of Problem

America is aging. By 2050, the number of Americans age 65 and older is projected to reach 88.5 million, representing more than a fifty percent increase over 2010 (Vincent & Velkoff, 2010). The annual number of new cases of Alzheimer's and other related dementias is projected to more than double by 2050 (Hebert, Beckett, Scherr, & Evans, 2001). Dementia is a disease that is characterized by progressive deterioration of cognitive function (Morris, 2003) which can occur in a variety of combinations with different personality, behavioral, and mood changes (Gustafson, 1996). For a significant number of people with dementia the option of staying at home is lost as the disease takes their ability to function independently (S. L. Mitchell, Morris, Park, & Fries, 2004). It is always associated with a need for care (de Rooij et al., 2012). As the needs of this group increase, the demands for services increase. Families often attempt to fill this need (Alzheimer's Association, 2013b). But, as family caregivers (FCGs) attempt to manage increasing frailty associated with deterioration from dementia, they themselves may experience the effects of the increasing demands of care (Bauer & Nay, 2003; Donaldson, Tarrier, & Burns, 1997; Mass et al., 1994). With diminishing personal resources the need for assistance from residential services to care for their relative may be required. Assisted living (AL) is one such service rapidly growing in response to a need to provide 24 hour supervision and assistance with activities of daily living and health care (Assisted Living Federation of America, 2010; Polzer, 2008).

Multiple studies have been conducted that suggest families do not abandon their relatives after transition to assisted living and nursing homes (Gaugler, 2005). Studies involving family caregivers who transition their relative to either the nursing home or assisted living suggest the FCGs experience contradictory feelings of relief, sadness and guilt (Butcher, Holkup, Park, & Maas, 2001; Fink & Picot, 1995; Kellett, 1999; Liken, 2001; M. Nolan & Dellasega, 2000; Penrod & Dellasega, 2001) and may experience declines in physical and psychological health (Butcher et al., 2001; Grant et al., 2002; Schulz et al., 2004).

Seventy percent of assisted living residents transition from home (Assisted Living Federation of America, American Association of Homes and Services for the Aged, American Seniors Housing Association, National Center for Assisted Living, & National Investment Center for the Seniors Housing and Care Industry, 2009). This transition may occur in preparation for future needs or in response to functional and/or cognitive decline (Banerjee et al., 2003; Buhr, Kuchibhatla, & Clipp, 2006; Butcher et al., 2001; Coehlo, Hooker, & Bowman, 2007; Coward, Netzer, & Mullens, 1996; Cummings & Cockerham, 2003; Gaugler, Edwards, et al., 2000; Gaugler, Leach, Clay, & Newcomer, 2004; Russell, Cutrona, de la Mora, & Wallace, 1997; Yaffe et al., 2002; Y. Young, 2009). Currently, forty-two percent of residents in assisted living have moderate to severe cognitive impairment (Zimmerman et al., 2003).

People experiencing transitions tend to be more vulnerable to risks that affect their health and well-being (Davies, 2005). Although significant research has been conducted in the nursing home environment, little is known about the

influence of the transition to assisted living on the caregiver of a person with dementia (PWD). Davies (2005) suggests the manner in which the transition occurs is reciprocally affected by both the manner in which the PWD transitions as well as interactions with long-term care staff. Liken (2001) found that despite improvements in the personal lives of caregivers following transition to assisted living, high levels of internal conflict continued. Schulz and colleagues in a large study of caregivers who transitioned the PWD to long-term care environments, including 21.1% to assisted living environments, found depression and anxiety remained stable and the use of anxiolytics increased. Similar studies involving the family caregiver who transitions a PWD to the nursing home have shown significant impacts on both emotional and physical well-being, including increases in depression, anxiety, and systolic blood pressure (Butcher et al., 2001; Grant et al., 2002; Schulz et al., 2004). Multiple factors appear to influence the transition. What is not known is the role visitation plays during the transition.

Visitation. There are essentially three types of approaches to visitation during the admission transition used by AL. One is to encourage family members to participate and remain involved with their loved one, keeping established routines as consistent as possible. Concerns have been raised that this interferes with the transition as the person with dementia often repeatedly asks the family to take them home. The second approach is to request that family members refrain from visiting until the person with dementia “settles in”. This approach has been highlighted in lay publications that suggest it is the way to bridge that transition. For example, in the April, 2013 Reader’s Digest article “50 Secrets a

Nursing Home Won't Tell You", a Wisconsin nursing assistant states "it's a good idea not to visit for the first two weeks, especially if your relative has dementia. Just call, or write a letter if you want to. That gives her time to build a relationship with the staff and other residents and get used to the fact that this is her home. Otherwise, every time she sees you, she'll think she's going home, and when you leave, she'll get really upset. It ends up taking longer for her to adjust" (Crouch, 2013). Anecdotally, this approach can create distress for both the person with dementia and his/her family when feelings of abandonment and loss are expressed.

The third approach is to neither encourage nor discourage visitation, but leave that decision in the hands of the family caregiver. Unfortunately, there is a dearth of research surrounding the best approach for family caregiver involvement during the admission transition to either assisted living or nursing homes. Therefore, it is not clear which approach, if any, is associated with a successful transition for both the person with dementia and their family members. It is also not clear whether one approach might be better in some situations than in others.

Specific Aims

This study was the first in a planned program of research intended to explore the transition of a person with dementia to assisted living. The purpose of this study was to describe how the assisted living home's policies and practices regarding visitation between the family caregiver (FCG) and the person with

dementia (PWD) influenced the admission transition for the FCG. The specific aims of the study were as follows:

1. Describe the FCG's experience when a person with dementia transitions to an assisted living (AL); and
2. Describe how the FCG's understanding of the family visitation recommendations of the AL (encouraged, discouraged, or neither encouraged nor discouraged) influenced the family caregivers' perceptions of, and reactions to, the admission transition.

Background and Significance

Someone in the US develops Alzheimer's every 68 seconds; by 2050 it will be every 33 seconds (Alzheimer's Association, 2013b). Without the development of interventions that either slow or cure the disease, it is estimated that the number of persons afflicted with Alzheimer's will increase from 4.7 million to 13.8 million by 2050 (Hebert, Weuve, Scherr, & Evans, 2013). Alaska experienced a 47% increase in dementia prevalence between 2000 and 2010 and is projected to experience a 126% increase between 2000 and 2050 (Alzheimer's Association, 2013b). This increase will have a significant effect on health care systems, families, and caregivers (Alzheimer's Association, 2013b).

Unpaid caregivers are usually family members. Nationwide, caregivers provide eighty percent of the care provided in the community—fifty percent live in the same home (Institute of Medicine, 2008). In 2012, they provided “17.5 billion hours of unpaid care, a contribution to the nation valued at over \$216 billion”

(Alzheimer's Association, 2013b). From 2009 to 2011 the number of caregivers in Alaska dramatically increased from 16,313 to 32,089 (Alzheimer's Association, 2013a). In 2012, 33,000 caregivers of PWDs in Alaska provided 37 million hours of unpaid care valued at \$459 million.

Dementia is increasingly cited as a reason for long-term care, which the Centers for Medicare and Medicaid define as “services provided to individuals with chronic illness or disability that includes medical and non-medical care that can be provided at home, in the community, in assisted living or in nursing homes” (U.S. Government, 2012). In 2010, forty-two percent of residents in assisted living had Alzheimer’s disease and other related dementias (Polzer, 2013) and sixty-five percent of nursing home residents had moderate to severe dementia (United States Department of Health and Human Services & Services, 2012). When family caregivers are no longer able to provide the care needed to someone with dementia, transitioning into long-term care is often necessary.

According to Vincent and Velkoff (2010) and Fallick and Pringle (2006) in 2006 there were approximately 5 people working to support every person age 65 and over, with the elderly constituting about 12 percent of the population. In 2030, by the time most baby boomers will have retired, the ratio is projected to be approximately 3 working age adults per older person and the elderly are expected to comprise about 19 percent of the population. This significantly reduces the tax base to support individuals 65 and older. One potential impact may include the need to use the most cost effective means to support older adults requiring ADL/IADL care. This may result in an increased use of assisted

living rather than nursing home facilities. There may also be an increased potential for earlier transitions as individuals work longer before retirement. There have already been policy changes that have extended the age for retirement from 65 to 67 (Social Security Administration, 2009) and President Obama's has proposed a delay in awarding Medicare benefits from age 65 to 67 (Vernon, 2012). As 14 percent of caregivers are 65 or older and 38 percent are 50 to 64 (National Alliance for Caregiving, 2009) these revisions may reduce the pool of available full-time caregivers as they continue to work into their late sixties.

Assisted living. Assisted living plays a key role in the continuum of long-term care of older adults. Initially, assisted living was conceived as a place where individuals requiring assistance with activities of daily living and independent activities of daily living could be supported in a safe setting with the majority of care provided by unlicensed assistive personnel. As assisted living homes evolved they became settings where changing needs were accommodated by augmenting services with external resources (home health nursing, physical therapy, occupational therapy, social work; hospice, etc.) allowing the older adult to age in place and minimize the impact of multiple transitions (Volpin, 2012; K. B. Wilson, 2007; R. S. Wilson et al., 2007). With nursing home costs averaging twice that of AL, AL represents a cost effective alternative. In response to this alternative, there has been a significant increase in the number of assisted living homes. Operators of these homes are not always familiar with caring for clients with dementia including the value of family involvement.

Across the nation there are 51,367 residential facilities (assisted living facilities and assisted living homes) with a 1,233,690 bed capacity (Mollica, Houser, & Ujvari, 2012). Assisted living regulations are state specific, resulting in significant variation across the United States (K. B. Wilson, 2007).

Currently, individuals in Alaska making decisions regarding how transition occurs in assisted living homes may not possess a knowledge base from which to assess the best approach for the resident and the family caregiver during this critical time. In Alaska, AL homes with fewer than 11 residents are not required to have either professional nursing staff or nursing oversight. All homes, regardless of size, must employ at least one certified nursing assistant. All employees must complete 12 clock hours of continuing education yearly (State of Alaska Department of Health and Human Services, 2002); although there is no requirement for training in the care of persons with dementia or dementia related behaviors.

Dementia and the transition to assisted living or nursing home.

Studies reflect the most common care recipient characteristics cited by FCGs for transitioning a relative with dementia from home care to assisted living or nursing home are dementia related behaviors, decreased ability to complete activities of daily living, depression, and incontinence (Bramble, Moyle, & McAllister, 2009; Buhr et al., 2006; Donaldson et al., 1997; Maas et al., 2004). For the family caregiver feelings of being overwhelmed by care, feeling physically and psychologically exhausted, feeling trapped in their role and possessing a sense of diminished quality of life are frequently identified as factors leading to transition

(Bauer & Nay, 2003; Donaldson et al., 1997; Gaugler, Yu, Krichbaum, & Wyman, 2009; Mass et al., 1994).

Although this study will focus on the FCG, it is important to understand the impact of transition on the PWD because it is posited that the meaning ascribed to the transition event by the FCG is influenced by how the PWD transitions (Davies, 2005; M. R. Nolan, Davies, Brown, Keady, & Nolan, 2004). When FCGs perceive the transition as a moral conflict, such as when the promise has been made never to transition the PWD from home, FCGs express feeling of guilt, sadness and loneliness (Kellett, 1999; M. Nolan & Dellasega, 2000; Penrod & Dellasega, 1998; Ryan & Scullion, 2000). Greater caregiver distress in the transition to nursing home appears to be influenced by increased guilt and when the relative experiences greater functional or cognitive decline (Butcher et al., 2001; Levesque, Ducharme, & Lachance, 1999; Maas et al., 2004; Tornatore & Grant, 2004). It is unknown if a similar pattern occurs in the assisted living setting.

People with dementia often have less resilience than their cognitively intact counterparts and possess a more limited ability to understand their environment. For the person with dementia the transition to an institution is disorienting and anxiety provoking (Cowdell, 2010; Digby, Moss, & Bloomer, 2012; Edvardsson & Nordvall, 2008). It can contribute to a sense of feeling unsafe, (Edvardsson & Nordvall, 2008) alienated, bewildered, powerless and alone (Digby et al., 2012). In many instances the PWD feels patronized and depersonalized by staff (Digby et al., 2012). As a result, the caregiver may find

the transition more challenging than they would if there were no changes in cognition or psychosocial functioning.

Caregivers who transition their relative to assisted living fear the prospect of another transition as their relative deteriorates (Liken, 2001). Consequently, when the move to ALH occurs, it is often intended to be the last move (H. M. Young, 1998). But, over time, 78% of individuals in ALs will transition to a higher level of care due to increased needs and 23% will transition from the AL due to dissatisfaction (Philips, Hawes, Spry, & Rose, 2010). Individuals with higher levels of cognitive impairment are three times more likely to make another transition to nursing home (Philips et al., 2010) with an associated increase in the cost of care. Lack of a nursing presence in the AL results in an 80% greater likelihood of transfer to another care setting (Philips et al., 2010). Whether any of these factors influence the transition from home to AL is unknown. As it becomes evident that cognitively impaired individuals are at increased risk for experiencing multiple transitions, understanding factors that support the transition for caregivers of persons with dementia becomes progressively more important.

Transition experiences of caregiver of person with dementia.

Contrary to popularly held beliefs, longitudinal analyses clearly delineate that the role of caregiving does not end with institutionalizing cognitively impaired relatives. Instead family members continue to be active in their lives (Gaugler, 2005; Kellett, 1999; M. Nolan & Dellasega, 1999; Woods & Warren, 2007; Yamamoto-Mitani, Aneshensel, & Levy-Storms, 2002). The direct technical care is often assumed by the staff, but many family members continue to make

regular visits, address transportation needs, coordinate finances, ensure quality care is provided, and provide emotional support (Bauer & Nay, 2003; Boise & White, 2004; Garity, 2006; Gaugler, 2005; Port, 2006; Port et al., 2005; Schulz et al., 2004).

How family caregivers respond to the admission depends on multiple factors, including the changes in the PWD that lead to the transition (Gaugler, Leitsch, Zarit, & Pearlin, 2000; Max, Webber, & Fox, 1995; Port et al., 2001), the level of caregiver exhaustion (Almberg, Grafstrom, Krichbaum, & Winblad, 2000; Gaugler, 2005), and the nursing home's practices related to admission and visitation (Davies, 2005). When the decision to transition from home to nursing home involves behavioral problems, caregivers report ongoing feelings of being overwhelmed and they reduce their involvement after the transition (Almberg et al., 2000; Majerovitz, 2007; Whitlatch, Schur, Noelker, Ejaz, & Looman, 2001). Some researchers speculate that spouses, and in particular wives, tend to be more emotionally invested in caregiving (Gaugler, 2005; Gaugler, Mittelman, Hepburn, & Newcomer, 2010; Pillemer, Hegeman, Albright, & Henderson, 1998; Pillemer et al., 2003; Pinquart & Sorensen, 2003), they report greater depressive symptoms, concerns over quality of care, and continued feelings of being overwhelmed (Gaugler, Leitsch, et al., 2000; Schulz et al., 2004).

Almost all the research related to transitioning an older adult from the home to an institution has been conducted in nursing homes. Spousal caregivers also appear to experience increased grief and depression after transition (Ott, Sanders, & Kelber, 2007). Gaugler, Mittelman, Hepburn, and Newcomer (2010)

found wives and daughters were more likely to experience clinically persistent burden after admission to nursing homes while husbands were at higher risk for clinically significant depression after admission. Greater caregiver distress after nursing home admission appears to be influenced by dissatisfaction with the care provided (Gaugler, Leitsch, et al., 2000; Schulz et al., 2004), conflict with staff and increased guilt (Butcher et al., 2001; Maas et al., 2004; Paun & Farran, 2006; Ryan & Scullion, 2000; Specht et al., 2000); greater functional or cognitive decline in the person with dementia (Levesque et al., 1999; Tornatore & Grant, 2004), and decreased involvement on the part of the relative (Tornatore & Grant, 2004).

How the transition is perceived by the family caregiver influences the caregiver's response (Mass et al., 1994; Port et al., 2005). Perception of care and level of involvement contribute to this perception during nursing home admission, but the understanding of its influence during admission to assisted living is less clear and warrants further exploration. Regulations exist to guide the quality of care in ALs, but variations occur between homes (Stone & Reinhard, 2007; K. B. Wilson, 2007). The degree to which family members are encouraged to remain engaged varies from home to home. The effects of these components may either contribute to or ease caregiver distress during and after transition to assisted living. Therefore, it is important to understand what impact, if any, the ALs approach to visitation has for the family caregiver.

Changes in the PWD's cognitive and functional levels influence caregiver distress (Levesque et al., 1999). Some research suggests that transition for a

person with dementia can exacerbate functional and cognitive decline (R. S. Wilson et al., 2007). The person with dementia's diminished ability to feel at home when they are at home or in another location may be linked to a compromised perception of the world (Svanstrom & Dahlberg, 2004). Adjusting for challenges in processing information becomes problematic as the disease progresses and may lead to significant distress (McCloskey, 2004). Possessing a sense of safety and security is important in minimizing this distress. In Digby, Moss and Bloomer's (2012) study, persons with dementia articulated that having family or close friends present or frequently checking on them provided a source of consolation. It offered the PWD a feeling that someone cared about them and was acting in their best interest. This was further supported by Edvardsson's (2008) work surrounding therapeutic environments for older adults with dementia. Therefore, exploring the impact of different visitation approaches during the "settling-in" period may contribute to our understanding of how to best support both the PWD and his/her FCG during this turbulent time.

Additional transitions may be required when behavioral, physical or cognitive changes make continued stay in assisted living unfeasible (Kelsey, Laditka, & Laditka, 2010). Forty-five percent of AL administrators report they will not retain residents who are aggressive, wander, or have difficulty socializing (Philips et al., 2010). When the transition from home to AL is turbulent and the PWD continues to experience behavioral changes such as agitation or wandering they are at increased risk for transition to a higher level of care. Kelsey and colleagues (2010) reported in their study of PWDs transitioning from assisted

living to memory care units, that family members found the transition traumatic. FCGs expressed feelings of anger, guilt, denial, and grief. This can lead to further exacerbation of the effect of emotional trauma on physical and psychological well-being. Therefore, understanding the factors that facilitate or undermine transitions may be helpful in reducing the frequency of transition from assisted living to other long-term care environments and untoward effects on the FCG.

Implications for Nursing

This study will extend our understanding of the needs of family caregivers and inform evidence-based dementia care during the transition period to AL. Developing best practices for transitioning a relative to ALs may assist in reducing transition stress for families. As knowledge of best practices and transition guidelines is lacking, understanding factors that create turbulence or facilitate transition may reduce the likelihood of multiple transitions between AL, nursing home, and inpatient settings; reduce the stress of transition; assist continuing education providers in developing courses to disseminate findings; and assist policy makers in developing transitional guidelines for assisted living homes.

Chapter 2: Review of the Literature

Uncharted Territory

Although the lay literature acknowledges the practice of discouraging family visitation during the “settling in” period, particularly for the person with dementia (PWD) (Crouch, 2013), a comprehensive search of Medline, CINAHL, EBM and PsycINFO yielded no studies that specifically addressed either the approach to family visitation during this period or the impact on FCGs who were either encouraged, discouraged, or neither encouraged or discouraged from visiting the PWD during the transition period from home to assisted living. The closest acknowledgement in the research literature that this practice exists, either in nursing homes or assisted living, is found within the study on the impact of family visitation on agitated behaviors of nursing home residents conducted by Martin-Cook and colleagues (2001). In their discussion of study limitations they acknowledge that some family members were excluded who were told by physicians or unit staff not to visit because of a subsequent increase in their relative’s agitation.

Despite this gap, there is literature that can help inform what is known about how the transition to AL impacts the FCG. Therefore, this review will: explore how the impact of transition on the person with dementia and consequently the family caregiver; examine the literature on family visitation patterns following admission; and examine the impact of family visits on the person with dementia. Inclusion criteria for this review are 1) research conducted in either nursing home or assisted living or research that compared the two

settings and 2) included the person with dementia, family caregiver or visitation.

This chapter will conclude with a discussion of how this research will contribute to addressing the gaps identified throughout this review.

Nursing Home Relocation: Effect on PWD

Because nursing home studies suggest that the caregiver is affected by the way in which the PWD transitions this review will examine the effect of relocation on the PWD. Relocation trauma was heavily studied 30 to 40 years ago (e.g. (Aldrich & Mendkoff, 1963; Beirne, Patterson, Galie, & Goodman, 1995; Borup, 1982; Borup, Gallego, & Heffernan, 1980; Brand & Smith, 1974; Friedman et al., 1995; Gass, Gaustad, Oberst, & Hughes, 1992; Kasteler, Gray, & Carruth, 1968; Manion & Rantz, 1995; Mikhail, 1992; Pruchno & Resch, 1988; Wittels & Botwinick, 1974)). Although this literature has been criticized because of some inherent methodological problems, concerns persist regarding the potential negative impact that relocation has on frail older adults. Research continues to show relocation may be associated with increased confusion, anxiety, apprehension, depression, loneliness, falls, mortality, morbidity, and decreased immunocompetence and psychosocial functioning (Aldrich & Mendkoff, 1963; Friedman et al., 1995; Manion & Rantz, 1995; *NANDA: nursing diagnoses, definitions, and classifications 1997-98*, 1996). Negative sequelae may be increased in individuals who feel powerless, have little preparation for the move, lack social support, and have decreased health (Barnhouse, Brugler, & Harkulich, 1992; Chenitz, 1983; Schulz & Brenner, 1977). Sequelae may also be more severe for older adults because of concurrent losses including loss of loved

ones, loss of familiar objects and loss of familiar surroundings (Birren, 1969; Brand & Smith, 1974; Engel, 1968; McCracken, 1987). Nursing home studies suggest that caregiver distress increases when the PWD experiences a decrease in cognitive or functional abilities (Butcher et al., 2001; Levesque et al., 1999; Tornatore & Grant, 2004). It is unknown how distress is affected when transitioning to an AL where the physical location may be perceived as more desirable because of its less restrictive, single occupancy, and home like environment.

Nursing Home Relocation: Effect on the FCG

Because the majority of the literature addressing the impact of moving an older adult out of the home setting has been conducted in nursing homes, this review focuses on that transition. Intuitively healthcare providers frequently recommend nursing home transition to relieve caregiver burden. A growing body of literature reveals that while caregiver burden changes with nursing home admission, it has failed to demonstrate dramatic positive changes in caregiver health or burden following the admission (Gaugler et al., 2010; Grant et al., 2002; Lieberman & Fisher, 2001; Schulz et al., 2004; Tornatore & Grant, 2002). When circumstances lead to the decision to transition a care receiver to the nursing home, some caregivers experience relief, others do not (Butcher et al., 2001; Fink & Picot, 1995; Gaugler & Kane, 2007; Gaugler et al., 2010; Kellett, 1999; Reuss, Dupuis, & Whitfield, 2005). Those who perceive the relocation as a moral conflict commonly face feelings of guilt, sadness, and loneliness (Kellett, 1999; M. Nolan & Dellasega, 2000; Penrod & Dellasega, 1998; Ryan & Scullion, 2000).

Elevations in systolic blood pressure, depression, and anxiety have been shown to occur in caregivers, particularly spousal caregivers, following transition of their family member in a nursing home (Butcher et al., 2001; Grant et al., 2002; Schulz et al., 2004). Both chronic grief and depression are common caregiver mental health effects that become exacerbated in the transition of a family member with Alzheimer's into long term care (Marwit & Meuser, 2002; Sanders & Adams, 2005; Walker & Pomeroy, 1996).

Courts, Barba and Tesh (2001) examined family caregivers' attitudes toward aging, caregiving and nursing home transition using a quantitative descriptive survey design. Although the response rate was lower (39.5%) resulting in a sample size of 33, they found caregivers in their study to be positive overall toward aging and caregiving. The majority of respondents reported a sense of feeling "privileged to care" and "really wanted" to care for their relative. They expressed mixed emotions when evaluating their feelings toward nursing home transition. When reporting the benefits, respondents described feelings of "being pleased", "relieved", and "somewhat happy". More than half reported a feeling of sadness when considering the challenges and 14.7% reported a sense of guilt. Limitations of this study included the setting (a private, non-profit church related facility) with no comparison group, small sample size, homogenous demographic (Caucasian, well-educated, and financially secure) and self selection. Social desirability may also have affected their responses, but it does support that, despite feeling sadness about relocating their relatives, family caregivers can perceive the move as positive. This study will contribute to the

growing body of literature on the positive aspects of relocation, by examining how the AL's visitation recommendations during the transition either support or undermine the outcome for the FCG.

Impact of Relocation to Assisted Living

Assisted living relocation: Effect on PWD. A number of studies have looked at the effect of the AL relocation on the person with dementia. Although this literature is not in the scope of this review, it was evaluated to look at factors that may facilitate or hinder the transition for persons with dementia from the family caregiver's perspective. According to Lee and colleagues (2002) transition to assisted living is the most significant move involving older adults. Individuals who reside in assisted living come from a variety of socio-economic, educational, cultural, and professional backgrounds (Pesenti, 1990). With the move comes not only a change in residence, but a change in routines and social context (Johnson, 1996). This move has been found to be one of the greatest sources of fear and stress in this population (Lee, 1997; Thomasma, Yeaworth, & McCabe, 1990). Home care has been advocated over residential care which may result in the reinforcement of older adults negative perceptions. Stories of abuse and neglect further perpetuate these perceptions (M Nolan, 1999). The impact of being on the wait list was found to result in lower self-image, emotional blunting, and being cognitively less intact compared to controls (Tobin & Lieberman, 1976). Apprehension was further stimulated by stories of negative experiences of others who moved (Lee, 1997). Nolan (1999) found these negative perceptions influence adjustment. Positive feelings have also been found including the relief

of not being alone and increased social stimulation (Victor, 1992). It is not surprising, given the crises involved in relocation, that studies have identified more negative than positive experiences.

Assisted living relocation: Effect on FCG. Liken (1998) conducted a qualitative study using a ground theory approach. She interviewed 20 family caregivers of PWD who had recently moved their relative to AL to explore ways to facilitate the transition. This study revealed recurrent themes of conflict, obligation, accommodation, and deceit. Critical times were experienced as family members sought a diagnosis, experienced the final straw, and physically made the move to AL. After the move, caregivers experienced a decline in direct care activities and improved personal lives, but continued to have high levels of conflict, obligation, accommodation, and deceit. There was also a prevalence of doubt about whether they had made the right decision and some were having second thoughts. The study limitations included small sample size, self-selection, the use of the AL as gatekeeper, and homogeneity of the sample. Of particular interest in this study was the discovery that the decision process to move a relative to AL appears much the same as the process to move to the nursing home. Both indicate the decision occurs after exploring all the options (staying home, in home care, AL, NH); after all personal resources have been depleted; after the caregiver reaches a crisis point that precipitates the move; and when FCGs felt nursing home to be a less than desirable option. The move to AL involved an additional step: ruling out NH as an option and one that was not yet needed.

Liken (2001) later performed a secondary analysis of her research using crisis theory to examine the process of transitioning a relative with Alzheimer's to AL. She found the caregivers frequently mentioned "distressing precipitants and mediating factors" that contributed to a crisis situation as well as failed problem solving attempts leading to transition. Despite the turmoil surrounding the transition itself, caregivers frequently reported positive outcomes for both the care recipient and themselves. For example, "it [the transition] was a horrible experience, but he is happy and we are happy with him being there. They love him a lot and that makes us feel we probably made the right decision." (p. 61). Conversely, negative outcomes were also discussed, including worsening memory loss, family member resentment, financial expenditure, and frustration with health care providers. Of particular interest in this analysis was the emergence of the reaction of caregivers who had not experienced a crisis. These individuals articulated significant guilt not seen in those who had experienced all elements of the crisis. Common to all participants was a reticence to discuss the future and an underlying concern about worsening memory problems and the potential for another transition.

Bramble, Moyle and McAllister (2009) conducted a qualitative descriptive study with 10 participants to determine what it means to be a family caregiver of a PWD who is placed in long term care. They evaluated three settings (assisted living (hostel), nursing home, and dementia special care units) in Brisbane, Australia. Similar to Liken (1998) their participants were primarily female and adult children (5 daughters, 2 sons, 2 female spouses, 1 male spouse). Similar to

Liken's (1998; 2001) findings Bramble and colleagues (2009) found a recurrent pattern of increasing burden often exacerbated by crisis. As adult children experienced role changes and an increased sense of obligation to care for their ailing parent, caregiver burden increased and often manifested as guilt, frustration and anxiety. Guilt was seen in expressions of regret at not being able to do more at home and increased demands from the system to provide for the gaps in professional home care. These caregivers, consistent with Liken's (1998) findings, exhausted their problem-solving strategies prior to relocation. During the transition the researchers found the caregivers experienced "relentless grief". Despite the majority of caregivers initially feeling a sense of relief knowing their relative would be safe and looked after, they expressed feelings of loss, sadness and guilt. In this study all the female respondents discussed the need for counseling and over half sought professional assistance. Similar to the visitation literature, families desired to stay involved and communicate their relative's disabilities and needs. Initially, they did not feel facilities encouraged them to be involved resulting in a sense of isolation and powerlessness. They sought a connection with staff to ensure their relative was looked after and to give them a sense of meaning.

Paun and Farran (2011) conducted a pilot study of the Chronic Grief Management Intervention for 34 dementia caregivers in transition over a seven month period. During the intervention application, caregivers felt a need to discuss their feelings of loss and especially guilt by the third week even though the first six weeks were designed to address more concrete topics. Limitations of

this study included small sample size, limited inclusion of African American caregivers, and the majority of subject recruitment was from suburban facilities with only one inner city facility participating.

The above findings and the findings of Butcher, Holkup, Park and Maas (2001), Maas and colleagues (2004), Marwit and Meuser (2002), Ryan and Scullion (2000), Sanders and Adams (2005), Specht and colleagues (2000), and Walker and Pomeroy (1996) support that grief, depression, and guilt are exacerbated for the family caregiver in the transition of a family member with dementia whether it is to assisted living, nursing home, or special care unit. What remains unknown are the impacts on the FCG of the AL's visitation practice especially those who are discouraged from visiting until their relative "settles-in".

Family Caregiver Involvement in LTC and AL

This section will examine visitation patterns, predictors of involvement (advocacy, direct care, visiting and socio-emotional support), and the impact of family visitation on the PWD in both nursing home and AL. Facility, resident, and family factors that potentially impact involvement will also be presented.

Visitation patterns. A significant effort has been expended to either confirm or dispel the idea that family and friends abandon the person who enters the nursing home. Although Port and colleagues (2001) found contact between pre-admission and post-admission decreased by almost half, evidence from both large and small scale cross-sectional studies concludes that most nursing home and assisted living residents continue to have at least weekly family contact for three to six months following the initial transition (Bitzan & Kruzich, 1990; Duncan

& Morgan, 1994; Gaugler, 2005; Gaugler & Kane, 2007; Gottesman, 1974; Kane, Illston, Kane, & Nyman, 1989; Keefe & Fancey, 2000; Monaha, 1995; Moss & Kurland, 1979; Rowles, Concotelli, & High, 1996; Smith & Bengtson, 1979; Spasoff et al., 1978; Thompson, Weber, & Juozapavicius, 2001; Vinton & Mazza, 1994; York & Calsyn, 1977; Zarit & Whitlatch, 1992).

Longitudinal studies of family visitation patterns in nursing homes and assisted living document that visitation patterns vary little over time and support the continuation of regular family contact (Aneshensel, Pearlin, Mullan, Zarit, & Whitatch, 1995; Ross, Rosenthal, & Dawson, 1997). Ross and colleagues (1997) used a mixed method design to examine spousal visitation patterns over a nine-month period in the nursing home. They report that 20% visit on a daily basis and 80% visit weekly. Duration of visits averaged two to four hours. Aneshensel et al. (1995) conducted a three year study of 555 caregivers. During the two year period following admission caregivers of PWDs visited an average of five hours each week and at three years, the average time spent was 4.2 hours. A comparison of visitation patterns between nursing home and assisted living residents in Oregon found approximately 41% of assisted living residents and 31% of nursing home residents had weekly visits (Kane et al., 1989). Hopp (1999) reported 36.9% of AL residents were visited two to three times each month. Mitchell and Kemp (2000) in their California based study of assisted living found 77% had monthly contact. Thompson and colleagues (2001) in their study of assisted living found family visited an average of 14.3 times a month. Yamamoto-Mitani and colleagues (2002) in their 5 year longitudinal study of

visitation patterns of caregivers whose relatives with dementia initially resided in the community and then transitioned to nursing homes concluded patterns of visitation established during the first year were consistent with future patterns.

These studies are not without limitations. Information regarding visitation tended to be gathered from only one source and with few exceptions collected retrospectively. This design may result in bias from accuracy of recall and time estimations as well as a desire to appear more attentive than perhaps the respondents actually were. However, this evidence supports that families choose to remain involved once their relative relocates to either nursing home or assisted living. Additionally, studies that specifically examine the effect of discouraging family visitation have not been conducted in assisted living or nursing homes.

Predictors of involvement. There are a variety of reasons family members continue to remain involved. Gaugler and Kane (2007) in their review noted resident's families typically reside in close proximity and not only visit, but provide varying levels of informal support, including socio-emotional support, instrumental activities of daily, and direct care. Ross, Rosenthal and Dawson (1997) found love and devotion; duty and obligation, monitoring well being, and providing assistance were among the most important impetuses to involvement for wives whose husbands were living in nursing homes. Kelley and colleagues (1999) found similar patterns in their qualitative study, including being family, being faithful, and being the 'eyes and ears' of their relative as did Kellett (1999) who added feeling as though the family caregiver had a break from caregiving,

having a sense of self-worth by providing special knowledge, and providing a sense of continuity for their relative.

Multiple characteristics were found to influence involvement in nursing homes. Spousal caregivers and adult children tended to visit more frequently and for longer periods of time (Port et al., 2001; Ross et al., 1997; Yamamoto-Mitani et al., 2002). Max and colleagues (1995) noted caregivers who were younger and were not spouses were more likely to provide informal support. Proximity to the nursing home was a common predictor of visitation in multiple studies (Gaugler & Kane, 2007; Hook, Sobal, & Oak, 1982; Port et al., 2001; Yamamoto-Mitani et al., 2002). Caregivers who had less formal education more often provided informal support (Gaugler, Leitsch, et al., 2000; Yamamoto-Mitani et al., 2002). Both qualitative and quantitative studies found the quality of the prior relationship to be a strong indicator of involvement following admission to the nursing home (Kellett, 1999; Kelley et al., 1999; Yamamoto-Mitani et al., 2002; York & Calsyn, 1977). Yamamoto-Mitani and colleagues (2002) found caregivers who held strong sentiment against transition were more likely to visit and Kelley and colleagues (1999) in their qualitative study described how those with a negative perception tended to visit more frequently and make more unannounced visits than those more positively disposed toward transition. Care receivers who had less cognitive impairment and fewer behavioral problems pre-transition received more informal support from family caregivers (Gaugler, Leitsch, et al., 2000; Max et al., 1995; Port et al., 2001).

Facility factors. Quantitative studies that examined the facility level factors found facilities that treated the family as clients were more likely to see increased family involvement (Friedemann, Montgomery, Maiberger, & Smith, 1997; Friedemann, Montgomery, Rice, & Farrell, 1999; Montgomery, 1982) than facilities that viewed families as an inconvenience. Similarly, facilities that were non-profit organization with fewer public payment residents (Gottesman, 1974) had greater family involvement than facilities that were for-profit or had more public pay residents.

Studies that evaluated factors that influence family involvement in assisted living were fewer. Gaugler and Kane (2001) found, as with nursing homes, proximity to the assisted living home was significant over time. Residents who were more frail, older, and had less formal education were also found to have more informal support over the course of the study. Hopp (1999) found that residents who were female and Caucasian were more likely to have increased informal support than male or minority residents. In contrast to the findings in nursing homes, Pruchno and Rose (2002) found that greater length of stay in assisted living was associated with a less family interaction.

Nursing home studies also report a close pre-morbid relationship and a negative sentiment against transition is associated with increased visitation, but this was not appraised as a predictor in the assisted living studies. Residents in nursing homes who had higher pre-morbid levels of cognitive impairment and behavior problems were found to have fewer visits. This also was not appraised in the assisted living visitation studies. Additionally, what these studies do not tell

us is what the underlying factors are for why family members decrease involvement when there are more cognitive or behavioral problems pre-transition. One might hypothesize that it is related to a sense of relief for the caregiver, resulting in self-limiting visitation behaviors following admission or to an exacerbation of symptoms for the PWD during transition, making it more difficult for the caregiver to visit. It is not clear how much this reduction in visitation is related to facility visitation guidelines. At this point it is known that involvement decreases, but the reasons underlying the decrease remain unknown.

Impact of FCG Visitation on PWD

Anecdotally, staff members from both nursing home and assisted living environments articulate negative outcomes such as increased agitation or disruption of the “settling-in” process as reasons for limiting visitation during the transition. For this reason, this portion of the review will examine the impact of FCG visitation on the PWD. It has been posited that family visitation is associated with positive outcomes for the PWD. However, it is difficult to develop a consistent picture of the impact of family visitation following admission to nursing home, special care units, or assisted living. For example, the life satisfaction, mortality, and morbidity literature overall identifies positive effects of frequent visitation (Greene & Monahan, 1982; Jablonski, Reed, & Maas, 2005; Kiely, Simon, Jones, & Morris, 2000; Noelker & Harel, 1978; Zimmerman, Gruber-Baldini, Hebel, Sloane, & Magaziner, 2002); however, studies of behavioral responses reflect both positive and negative outcomes (Cohen-

Mansfield et al., 2010; Cohen-Mansfield & Werner, 1997; Gilleard, Gilleard, Gledhill, & Whittick, 1984; Jablonski et al., 2005; Martin-Cook et al., 2001).

Early work examining the effects on well-being of residents in nursing homes suggested the positive therapeutic influence of family visitation on nursing home residents and provided a foundation for future studies (Gaugler, 2005). Noelker and Harel (1978) examined life satisfaction of 125 nursing home residents in 14 nursing homes and discovered those whose desire for visitors was met scored higher on the life satisfaction scale. Greene and Monahan's (1982) findings also supported the positive impact of frequent visitation in their study of 298 residents in 28 nursing homes in Melbourne, Australia. They found psychosocial impairment was significantly lower in those who were visited more frequently.

Kiely et al. (2000) evaluated the relationship between social engagement and mortality in a Boston nursing home. After controlling for mortality risk factors, this retrospective study of 927 nursing home residents concluded those who did not engage socially were 1.4 times more likely to die when compared to the most socially engaged. This study used mortality data derived from facility records over a 1721 day follow-up period. Although limited to one facility, the sample size and length of follow-up period suggest a positive relationship between engagement and life expectancy.

Zimmerman and colleagues (2002) conducted a study of 2015 new admissions to multiple Maryland nursing homes. Their findings reflected a lower relative risk of infection and hospitalization for infection with more frequent family

visits. Jablonski, Reed and Maas (2005) found increased family involvement slowed global deterioration in their study of 164 residents in 14 Midwest nursing homes with special care units. These studies suggest morbidity is negatively correlated with visit frequency.

However, when examining behavioral outcomes for the PWD, the positive effect is not as readily apparent. For example, Jablonski, Reed, and Maas (2005) found despite decreases in global deterioration with family visits; inappropriate behavior, cognition, and functional status remained relatively unchanged. Martin-Cook and colleagues (2001) found a positive effect when evaluating the impact of family visitation on agitation levels before, during, and after the visit with 30 resident-visitor dyads from both assisted living and nursing home special care units in the Dallas, Texas area. Overall, the results of this study suggested that visits have a calming effect. Levels of pre and post-visit agitation remained relatively stable with improvement during the visit, but returning to pre-visit levels within 30 minutes following the visit. Consistent with decreased agitation findings of social interaction and family presence, Cohen-Mansfield and Werner (1997) conducted an intervention study including 32 nursing home residents in Maryland nursing homes and found social interaction decreased verbally disruptive behaviors by 56 percent and simulated family presence reduced it by 46 percent. Cohen-Mansfield and colleagues (2010) also found live social stimuli to be associated with significantly less physical agitation than baseline observations in their repeated-measures experimental study conducted in 7 Maryland nursing homes with 111 residents with dementia who displayed agitated behaviors.

However, Martin-Cook and colleagues (2001) found PWD agitation levels were positively correlated with the visitor's view of the visit so although overall family visitation appeared to have a calming effect, this was not always the case. In the 70 percent that found visits to be at least somewhat pleasant agitation levels were diminished between pre and post-visit assessments. However, in the 20 percent of visitors who described the visit as unpleasant agitation scores increased between pre and post-visitation. Family members who described the visits as unpleasant associated this with the level of cognitive impairment, difficulty communicating, agitation during the visit and not knowing what to do. This study was further limited by its design. Only individuals with mild to moderate dementia were included. Individuals who experienced significant agitation after visits were excluded from this observational study secondary to staff and physician recommendations to curtail family visitation. It is unknown what factors may have been associated with the increased agitation experienced in this group.

Correlations have been found between the number of general problem behaviors exhibited by persons with dementia and the quality of the pre-morbid relationship between caregiver and care recipient. Poor quality of pre-morbid relationships has been negatively correlated with the number of general problem behaviors exhibited by the PWD including verbal and physical agitation (Gilleard et al., 1984). Whereas, Martin-Cook, et al. (2001) did not find an association between the pre-morbid relationship and agitation. Although, the majority of participants in Martin-Cook and colleagues' (2001) study stated they had a very

close pre-morbid relationship which may have skewed this finding. Overall, this review suggests that we do not yet understand the situations in which family visitation can be important to the well-being of the PWD and those where visitation can be detrimental. The outcome of visitation on the FCG is also lacking.

Summary

The research shows visitation patterns are similar between nursing homes and assisted living. Visitation patterns throughout the admission appear to be established within the first year. On average, the family continues to visit at least weekly after admission, although it is not clear whether this rate is influenced by the family visitation policies of specific facilities. There are a variety of predictors for involvement which include proximity; prior relationship; strong sentiments against transition; level of pre-admission cognitive impairment and behavioral problems; and the need to provide identity, care assistance and monitor well being.

For the PWD, family visitation has been shown to increase life satisfaction, slow global deterioration, decrease rates of morbidity and mortality and decrease agitation during visits. Some research has reported a relationship between the pre-morbid relationship of the FCG and the PWD and the number of general problem behaviors experienced (Gilleard et al., 1984; Martin-Cook et al., 2001).

Relocation, regardless of setting, has been associated with increased confusion and disorientation; increased agitation and anxiety; and increased depression for the PWD. A significant amount of research has been conducted to

dispel the assumption that transition of a relative to nursing home consistently results in positive outcomes for the FCG. Although some caregivers experience either psychological or physical relief, others do not. Individuals who perceive the nursing home admission negatively have been shown to experience an increase in adverse physical and/or psychological indicators. This is particularly true of spousal caregivers. For studies that have specifically evaluated the transition phase, chronic grief and depression has been increased for FCGs.

Research involving the impact of transitioning the PWD to AL on the FCG has been limited. What has been discovered is, despite the turmoil surrounding the transition; FCGs frequently report positive outcomes for both the PWD and themselves. These include relief because someone is with the PWD 24 hours a day, reestablishment of personal lives, and relief because their relative seems happy. Regardless of positive outcomes, they still experience feelings of sadness, loss, and guilt. One study captured how FCGs felt when they weren't encouraged to be involved after the relocation (Bramble, Moyle and McAllister, 2009). In this instance they described a sense of isolation and powerlessness.

Adjustment to relocation is a dynamic process for both cognitively intact and cognitively impaired individuals. Wilson (1997) identifies three phases associated with the first month after relocation: the overwhelmed phase, the adjustment phase and initial acceptance. The overwhelmed phase is dominated by feelings of loneliness, depression, fear, and loss. Brooke (1988) called this the disorganization phase. This phase typically lasted 2 months, but in cognitively impaired individuals, increased confusion and agitation can occur with the move

(Cohen-Mansfield, Marx, & Werner, 1992) translating to increased feelings of guilt for the FCG. Although relocating to AL increased behavior problems, this effect seemed to dissipate after one year (Macdonald, Philpot, & Briggs, 2004). The family caregiver of the PWD may go through a similar process. The adjustment phase (S. A. Wilson, 1997) also known as the reorganization phase (Brooke, 1988) is characterized by problem solving and establishing networks. The initial acceptance or relationship building phase results in new friendships (Brooke, 1988; S. A. Wilson, 1997). It is possible as the PWD moves into the adjustment and acceptance phases, the FCG also experiences acceptance that they “did the right thing”. The degree of cognitive impairment (Brooke, 1988) impacts whether the PWD moved through these phases to stabilization and acceptance. This may also impact the progression of the FCG through this process.

This research will contribute to expanding the body of knowledge related to the overall impact of visitation on the family caregiver, which is largely excluded from the literature. The majority of studies that have been conducted regarding visitation have focused on nursing home residents and the impact of visitation on the PWD. Family caregivers who have been asked not to visit or limit visitation lack a voice in the research from what appears to be the effect of recruitment designs. The majority of studies have recruited from the facility. If the caregiver has been asked to limit visitation it would make sense that their voice has not been heard as they would not be exposed to the recruitment strategies. This study will shed light on the effect of encouraging or discouraging family

caregivers from visiting during the transition of a PWD from home to assisted living, the psychosocial adjustment of FCG, the effect on the FCGs satisfaction with care when they are encouraged or discouraged from visitation, how the FCG perception of the facility culture contributes to family involvement and lay the foundation for future studies.

Chapter 3: Research Design and Method

Overview: Design

This study used a qualitative descriptive design, as explicated by Sandelowski (2000), to describe how the assisted living homes' policies and practices regarding visitation between the family caregiver (FCG) and the person with dementia (PWD) influenced the admission transition for FCGs. The specific aims of the study were as follows:

1. Describe the FCG's experience when a person with dementia is transitioned to assisted living; and
2. Describe how the FCG's understanding of the family visitation recommendations of the AL (encouraged, discouraged or neither encouraged nor discouraged) influenced family caregivers' perceptions of, and reactions to the admission transition.

Qualitative Description

Qualitative description draws from the general tenets of naturalistic inquiry (Lincoln & Guba, 1985) describing the facts and the meaning assigned by the participants providing for straight description of the phenomenon (Sandelowski, 2000). According to Sandelowski (2000), qualitative description is categorical, less interpretive than other qualitative methods, does not require conceptualization or highly abstract interpretation, and stands alone as its own qualitative method. The goal is to represent the data just as it is, while answering the who, what, when, and where of people, places, and activities (Sandelowski, 2000). The choice of qualitative description for this study was two-fold. First, the

phenomenon had been acknowledged in the lay literature and in patient-clinician interactions, but had not been developed in the primary research literature. The goal of qualitative description is to provide a comprehensive summary of events in everyday terms that achieves descriptive and interpretive validity ensuring the facts are accurately conveyed as well as the meaning ascribed to them by the participant (Sandelowski, 2000). This approach was consistent with laying a foundation of a basic knowledge and developing an understanding of coping and adjustment to the transition experience for the FCG of the PWD when it is influenced by the AL visitation guidelines.

Second, using a low level of inference allowed the researcher to stay closer to the data and the words and events described by the participants than do the other forms of qualitative interpretive description methods (Sandelowski, 2000). This lent itself to achieving consensus surrounding the description of the event and the meaning assigned by the participant. This approach offered a description that can be easily understood by the general public and clinicians alike (Sandelowski, 1996); therefore, it is useful in conveying information to support intervention development and refinement (Sullivan-Bolyai, Bova, & Harper, 2005). This is consistent with the future goal of developing an intervention that would support assisted living personnel and family caregivers of the PWD to determine the best approach to visitation for their individual situation.

Sample Selection and Criteria

Sample. In this study, purposive sampling was used to identify family caregivers of PWD who had made the transition from home to AL to include

those who had been encouraged, discouraged and neither encouraged or discouraged to visit, using a maximum phenomenal variation technique (Patton, 2002; Sandelowski, 1995). Family caregivers were classified as the family member who was at least 18 years of age and self-identified as “very involved” in the care of the person with dementia prior to the move to AL. This person may have been related by blood or marriage or be a friend, neighbor or fictive kin (Talley, Chwalisz, & Buckwalter, 2011). The transition period was initially defined as the six-month period following arrival in the assisted living. This period was chosen based on both anecdotal findings (Silin, 2009) as well as transition literature which reflected adjustment takes approximately six months (Dimond, McCance, & King, 1987; Marshall & Mackenzie, 2008; Mirotznik & Ruskin, 1985; Street, Burge, Quadagno, & Barrett, 2007; Tracy & DeYoung, 2004). The transition period was extended to one year based on findings during the first two interviews that the transition period had not ended within the 6-month period. Ultimately, the transition period was removed after discovering the transition remained incomplete one year after the move.

Exclusion Criteria. Exclusion criteria for the family caregiver included a) non-English speaking and b) residing outside the states of Alaska, Washington, Oregon, or Colorado.

Inclusion Criteria. Inclusion criteria are a) PWD has relocated to assisted living, b) FCG is 18 years of age or older, c) FCG resides in the state of Alaska within the Matanuska-Susitna Borough, Municipality of Anchorage, Fairbanks North Star Borough or Juneau Borough, state of Washington, state of Oregon,

state of Colorado, d) FCG self-identifies as “very involved” in the care of the PWD prior to admission to AL, g) PWD transitioned from home or another AL, and h) transitioned to AL .

Recruitment. Recruitment of potential participants was initially conducted through the Assisted Living Home Providers Association of Alaska (ALHPAA) and the Alzheimer’s Resource of Alaska. Appointments were scheduled with the president of ALHPAA and director of Alzheimer’s Resource of Alaska to explain the study. Fliers were distributed to members of ALHPAA through mailing and attendance at the monthly ALHPAA meeting. Fliers were posted in the Alzheimer’s Resource of Alaska in Anchorage, Alaska. Fliers were mailed to all assisted living homes in Anchorage, Eagle River, Palmer, Juneau and Wasilla listed on the State of Alaska licensing website. Fliers were sent to the Care Coordinators for the State of Alaska. In addition, advertisements were placed in the Senior Voice (newspaper circulated throughout Alaska) and the Anchorage Senior Center’s Newsletter. Fliers were posted in Anchorage and Fairbanks, Alaska grocery stores and pharmacies. When an adequate number of participants was not recruited, recruitment was expanded to the states of Washington, Oregon, and Colorado as well as the Oregon Health & Science University Layton Aging and Alzheimer Disease Center through personal and professional connections. Advertisement was placed in the Anchorage Daily News. Snowball sampling of caregivers was also used during initial recruitment and when negative cases were sought.

Sample size. Information rich cases were sought to explicate the FCG of a PWD experience of AL transition paying careful attention to the impact of visitation until informational redundancy was achieved. Seven participants provided descriptions of 11 transition events.

Data Collection

The data were collected and analyzed by the researcher. Data collection and analysis were concurrent. The analysis informed further data collection. The primary collection technique was individual in-depth interviews using a semi-structured interview guide. As family caregivers did not become fatigued during this process, it was not necessary to schedule more than one interview to complete initial data collection. Some participants were interviewed multiple times to clarify meaning and to reach informational redundancy. The interviews were conducted in a place of the interviewee's choosing to facilitate their comfort. At each interview, the purpose and procedures of the research were reviewed with the interviewee and their desire to continue was confirmed. The interview consisted of open-ended questions structured around the transition and visitation guidelines. A preliminary guide was developed (see Appendix A). Follow-up and probing questions were used as necessary to elicit the richness and depth of data necessary to fully describe the transition phenomenon. Data collection proceeded until informational redundancy was achieved (Lincoln & Guba, 1985).

In addition to the interview data, field notes were maintained to develop an understanding of the transition. Field notes described what the researcher observed, experienced, and reflected upon during the interviews. These notes

were completed after every participant interview, to encourage reflection and understanding of the experience of collecting the data and interacting with participants. Information such as where the interview took place, who was present, a description of the setting, social activities, and interactions were recorded. In addition to the observations, the field notes included the researcher's feelings and reactions to what was being observed, and any insights and interpretations. Field notes helped provide a complete picture of the phenomenon and assisted the researcher in moving through the data analysis process (Patton, 2002). All interviews were digitally recorded and transcribed verbatim. Transcription occurred shortly after completing each interview. The authenticity of the transcription was verified by listening to the digitally recorded interviews while examining the transcript. During this process all personal identifiers were removed and a unique identifier code was assigned to protect confidentiality. Pseudonyms were substituted for any names referred to in the transcripts.

Demographics. Demographic data for both the FCG and PWD were collected from the FCG. These data included the age, gender, level of education, and caregiver identified stage of dementia (global deterioration) of the PWD, the FCG age, gender, relationship to PWD, length of time caregiving prior to transition, length of time since transition, level of education, the FCG's assessment of their relationship with PWD prior to transition as close or not close, and self-rated health. In addition, data were collected from the FCG and the State of Alaska Licensing website regarding the facility including a copy of

the resident visitation policy, the number of beds, case mix (dementia/non-dementia residents), payment sources (long-term care insurance, Medicaid, private), for profit/not for profit status (see Appendix B). These factors have been shown to be associated with differences in long-term care admission adaptation by the FCG.

In-depth interview. The purpose of the in-depth interview was to explore the factors influencing the family caregiver's experience with transitioning a PWD to an AL using a semi-structured interview guide and open-ended questions. A preliminary interview guide was developed to guide the interview (see Appendix A). The questions in this guide were derived from the literature review and clinical experience. The interviews were flexible enough to explore individual perceptions and emerging categories/concepts. The interview guide was pilot tested for usability and clarity with an individual who has had a similar experience (caregiving for a PWD relocated to assisted living and had been told not to visit during the transition period) who resided outside of Alaska and was excluded based on the initial recruitment plan. Study data from this person were not included in the analysis. Feedback from the pilot testing resulted in minor modifications to the interview guide for usability. Further, during the course of data collection and analysis, the interview guide was modified to include additional questions derived from the data. The interviews began with the researcher asking the FCGs in more general terms about the person with dementia and their relationship and then moved into more specific questions concerning the transition. Six interviews were conducted in person, and 1 was

conducted telephonically. After obtaining informed consent, all interviews were digitally recorded and transcribed verbatim by an OHSU IRB-approved transcription service. The researcher reviewed the transcription while listening to the recording to verify its accuracy. By listening to the interviews, the researcher became immersed in the data, and it assisted in generating emergent themes as it enabled the researcher to capture the non-verbal data (tears, pauses, smiles) not noted by the transcriptionist. The field notes were transcribed and used as an additional data source for intra and cross case analysis (Patton, 2002). Telephonic or secure e-mail was used to clarify responses and conduct member checking, when more convenient for study participants than face-to face interaction.

Global Deterioration Scale. The Global Deterioration Scale (Reisberg, Ferris, de Leon, & Crook, 1982) was used to describe the FCGs perception of the degree of dementia and the influence it may have on the FCG's experience with relocation (see Appendix C). It was administered to the FCG during the interview process. The scale has been validated for concurrent validity with biomarkers (Rikkert et al., 2011). It is a 7-point scale. Stage 1 is defined as no cognitive decline (appears normal clinically), stage 2 is very mild cognitive decline (phase of forgetfulness), stage 3 is mild cognitive decline (earliest clear-cut clinical deficits appear), stage 4 moderate cognitive decline (late confusional stage), Stage 5 moderately severe cognitive decline (early phase), stage 6 severe cognitive decline (middle phase), and stage 7 very severe cognitive decline (late phase).

Data Analysis

Qualitative Content Analysis. The data were analyzed using a qualitative content analysis strategy commonly used in qualitative description studies. It was a dynamic process of analysis of both verbal and latent data (Morgan, 1993). Inductive content analysis was used in this study as there was limited knowledge of the transition phenomenon and the impact of visitation guidelines on the FCG rather than the deductive approach, which is used to test theory (Elo & Kyngas, 2008). The unit of analysis was the move. Both manifest and latent (non-verbal) content were analyzed. Steps in the inductive qualitative analytical process included line by line coding and content analysis, creation of codes, sorting and synthesis of codes into major categories and themes, the development of descriptive analysis memos, and identifying exemplar quotes to support the identified themes and categories (Elo & Kyngas, 2008). The coding was reviewed frequently throughout the process to ensure the researcher stayed close to the participant's description rather than incorporating her own. The reflective process was facilitated through introspection and journaling. Methods to ensure rigor included additional researcher data analysis/inter-coder agreement, and member checking (Lincoln & Guba, 1985). Decision memos were maintained throughout the analytic process.

Coding and content analysis. The researcher used content analysis to analyze the transcripts. This process began by reading each transcript and then coding line by line as well as passages of data. The researcher used a combination of pen and paper and Microsoft Word. A descriptive analysis

memorandum was created after coding each interview. Standardized codes were developed based on the analysis and synthesized into categories and themes. Secure e-mail provided a venue in which the researcher's dissertation committee viewed transcripts and provided analytic consultation.

Sorting and synthesizing of codes into categories and themes.

Thematic analysis techniques were implemented and sub-categories were identified and combined into categories and overarching themes that depicted the family caregiver's description of the transition (Burnard, 1991; Downe-Wamboldt, 1992). As the analysis progressed particular attention was paid to the differences between those who described the move as "easy" and those that described it as "hard"; those who were long distance caregivers and those who were local caregivers; and differences between caregivers' descriptions based on the time elapsed since the move of the person with dementia into assisted living. The researcher returned to the data repeatedly to ensure that the categories and explanations made sense and to make sure they represented the nature of the family caregiver's perception of the transition. Saturation of the neither encouraged nor discouraged group was achieved after coding and analyzing seven interviews which encompassed 11 moves.

Identification of exemplar quotes. In accordance with Sandelowski's (2000) suggestion, exemplar quotes were chosen to explicate the family caregiver's experience and impact of visitation guidelines on the family caregiver's perception of the transition. The final themes were verified by two participant FCGs and two non-participant FCGs.

Rigor and Trustworthiness in Qualitative Methods

The qualitative criteria suggested by Lincoln and Guba (1985) was utilized to ensure the trustworthiness and rigor of the findings. Verifying qualitative validity involved evaluating whether the information collected through the qualitative process was accurate and depicted the participant perspectives through ensuring *credibility, dependability, transferability* and *confirmability*.

The researcher brought to the research process both her clinical experience as a nurse practitioner with a subspecialty in geriatrics and her personal experience with moving a person with dementia into an assisted living home. While this has the potential to bias the analysis, it also has the potential to lead to a deeper understanding of the findings. The researcher took the position of empathetic neutrality as described by Patton (2002). In this approach, learning through empathy enhances the researcher's insights (Patton, 2002). As the researcher is the instrument of data collection, adherence to systematic procedures and reflection are important to credibility. Feedback regarding data collection and analysis was obtained from members of the qualitative dissertation seminar as well as a qualitative research mentor throughout the process. Additionally, the researcher personally completed and coded the participant interview. This allowed reflection on how her experience may potentially impact the analysis and provided structure as the researcher compared her analysis of participant interviews to her own. This process helped facilitate remaining close to the participant's description as the analysis evolved.

Credibility. Credibility examines whether the findings are accurate representations of multiple constructions (Lincoln & Guba, 1985). Lincoln and Guba (1985) recommend five strategies to achieve credibility: prolonged engagement, persistent observation, triangulation, peer debriefing, and negative case analysis combined with member checking. Strategies employed in this study to ensure credibility were peer debriefing, negative case analysis, and member checking.

Peer debriefing. This technique is identified as a useful strategy by Lincoln and Guba (1985) to achieve credibility. This process helps keep the researcher honest by exposing her to questions that uncover bias, explore meanings, and clarify the basis of interpretations. The role of the debriefer is to help the researcher identify the role her values play in interpretation. All questions are in order as they pertain to relevant matters whether they are ethical, legal, substantive or methodological. It was imperative, given the risk of over-identifying with participants, that this researcher employed the strategy of using a disinterested debriefer who was not afraid to challenge her perspectives and play the role of devil's advocate. Both the debriefer, who was the dissertation chair, and researcher kept written documentation of each encounter not only for the audit trail, but also for reference regarding why the inquiry emerged as it did.

Negative case analysis and member checking. The objective of negative case analysis was to continuously refine the analysis "until it accounts for all known cases without exception" (Lincoln & Guba, 1985). Cases were sought that differed from emerging trends in the analysis (Sandelowski, 2000).

However, as Lincoln and Guba (1985) point out, it is difficult to reduce the number of exceptions to zero and they propose that a reduction to a minimum of 60 percent would substantiate the findings.

Member checking was conducted with two of the participant FCGs and two FCGs who were not participants in the study. Through the process of member checking, short descriptions of the categories and themes were shared with the two interviewees and two non-participant FCGs and subsequently validated by them. Indeed, participants and non-participants agreed that the descriptions resonated with them. No significant revisions were made as the result of this process because the researcher's interpretation and depiction of the family caregiver's experience was supported.

Content validation. In addition to the steps outlined by Lincoln and Guba (1985) a content validation process was used. The researcher worked with experienced qualitative researchers who were well prepared to assure methodological rigor. The transcripts were independently analyzed by the researcher and at least one other member of the dissertation committee. Any discrepancies in coding or category development were discussed and reconciled. Both the dissertation committee and fellow student members of the Qualitative Dissertation Seminar provided an opportunity to test working hypotheses that emerged in the researcher's mind. If the researcher was unable to defend the hypothesis, an alternative view was considered.

Transferability. Transferability can only be evaluated in the presence of thick descriptions which describe the phenomenon in sufficient detail to allow one

to begin to examine the extent to which the findings are applicable in other contexts (Lincoln & Guba, 1985). Lincoln and Guba (1985) propose that it is the responsibility of the researcher to provide the broadest description through the implementation of purposive sampling. Qualitative description stays close to the data, words, and events described by the participant (Sandelowski, 2000). This more easily allows for achievement of consensus. When consensus is achieved it supports an increase in transferability by creating a database that contributes to the ability of others to determine transferability (Lincoln & Guba, 1985).

Dependability and confirmability. Dependability and confirmability were ensured through the use of the inquiry audit. The audit trail allowed for an examination of the data, findings, interpretations, and recommendations (Lincoln & Guba, 1985). This trail helped determine that the interpretations were supported by the data and were internally logical and consistent. The audit trail plan adhered to Halpern's (1983) recommended audit trail categories as cited by Lincoln and Guba (1985): raw data; data reduction and analysis products (field notes, memos, working hypotheses, concepts, hunches); data reconstruction and synthesis products including themes, definitions, linkages, findings and conclusions, and the comparison of the findings to the existing literature; process notes; materials relating to intentions and dispositions; and instrument development information materials. Coding memos were kept that outlined the inferences made when creating categories and links between the data and the results (Elo & Kyngas, 2008; Polit & Beck, 2004; Weber, 1990). A reflexive journal was kept as recommended by Lincoln and Guba (1985).

Journaling and reflection. Reflection was enhanced by journaling. An introspective series of questions were reflected upon including: what went well?; what revisions needed to be made for the next interview?; how close was the researcher's experience to the participant's experience?; and how might similarities have influenced the analysis?; what biases became evident?; and what shifts in thinking occurred?. Separate sections addressed the daily schedule and study logistics and reflections that provided an opportunity for catharsis, effects of personal values, and growing insights. Because the researcher is the instrument of analysis this process of self-reflection is integral to the qualitative process (Patton, 2002).

Human Subject Protection

The research proposal and procedures for protecting the rights of human subjects in this low-risk, non-intervention study were submitted for approval through the Oregon Health & Science University Institutional Review Board. Once participants were determined to be eligible, the consent form was reviewed under the principles of full disclosure and signature obtained. A copy of the consent form was provided. Standard principles of protection including the right to withdraw or stop an interview were implemented. The forms were kept in a locked cabinet to which only the principal investigator and this co-investigator had access.

Guidelines for conducting ethical research and protecting privacy were strictly followed. The Responsible Conduct of Research training and Conflict of Interest evaluation were completed through the OHSU Integrity Office.

Initially, participants were recruited through the Assisted Living Home Providers Association of Alaska and the Alzheimer's Resource of Alaska in Anchorage. Additional participants were recruited through snowball sampling and if needed from assisted living homes and Alzheimer's Resource agencies in Wasilla, Palmer, Fairbanks, and Juneau. Fliers were distributed to these organizations and posted at the Alzheimer's Resource of Alaska. Advertisements were placed in the *Senior Voice* and the Anchorage Senior Center Newsletter. In addition, advertisement was also placed in the *Anchorage Daily News*. Those who were interested in participating in the study contacted the researcher by phone or secure e-mail, and a brief description of the study was given including a review of the eligibility criteria. Written informed consent was obtained and interviews arranged. The voluntary and confidential nature of participation was explained in detail in the informed consent (see Appendix D) including the right to refuse to join or withdraw early from the study without repercussion. This was reinforced verbally when approaching potential study participants.

Interviews were held in a private location of the interviewee's choosing. Original tape recordings were destroyed once the accuracy of the transcription is verified. Only transcripts that had all identifying information removed and replaced with coded interview identifiers were retained. Transcript interview identifiers were assigned by this co-investigator using the coding system dementia caregiver (DC) and an interview sequencing number. They will be stored in a secured file for a minimum of five years. The records are accessible

only to the researcher, research consultants, or federal agencies responsible for ensuring human subject protection.

A transcription service that adheres to OHSU privacy policies was employed to transcribe digital recordings. All interview transcripts were de-identified and coded for analysis or reporting purposes.

All interview data and recordings are kept in locked files. Original digital recordings were destroyed once the accuracy of transcription was verified.

Because participants were at risk to experience emotional upset when discussing the transition, the researcher paused the interview when needed and asked if the participant would like to continue. The researcher is a skilled clinician who is experienced in assisting persons who experience situational distress. No participants elected to discontinue. For those who elected to continue, additional time was provided to allow them to regain their composure. No participants appeared inconsolable. For those who appeared to be upset following the interview, the researcher offered resources at the conclusion of the interview. The researcher followed up 24 hours later to ensure the participant did not require additional follow-up. No additional follow-up was required.

The consent form included a statement that evidence of elder abuse would be reported to Adult Protective Services for follow-up. The researcher as a clinician was obligated ethically and professionally to report abuse if it was observed or if there were a reasonable suspicion of abuse. There were no signs of abuse detected in these interviews.

At the conclusion of the study, a letter of appreciation was provided to each participant. A \$10 gift card was included.

Chapter 4: Results

Introduction

The purpose of this chapter is to describe the FCG's transition experience and how this group of family caregivers was influenced by the assisted living home's visitation guidelines. For some the move was a recent experience (within one year) for others the actual move had long since passed (4 years), but they remained in transition. All of the participants could vividly recall the events surrounding the transition to AL. A qualitative descriptive approach was used to explore the family caregiver's (FCG) experience of transitioning a person with dementia into assisted living and how the assisted living's visitation guidelines may have influenced their perceptions of and reactions to the move.

Findings

Sample

Seven family caregivers were recruited to participate. Seven in-depth interviews were conducted. Of the participants, 3 were daughters caring for fathers, 2 were daughters caring for mothers; 1 was a wife caring for her husband; and 1 son caring for his mother. Six were age 50 and older and 1 was under age 50. Six were white and 1 was not. Of the 7 persons with dementia 4 were deceased and 3 were still living. Six of the participants were from Alaska and 1 was from Oregon. Although the sample size was small there was significant variation in kin relationship, education, assisted living home size, PWD status, and payment source. Of the 8 FCGs identified, one wife was unable to participate secondary to on-going litigation resulting from the AL facility's practice

of recommending FCGs not visit during the admission transition, leaving following 7 FCGs to participate.

1. A daughter, *Jacque*, initially moved her father, *Tom*, from his home located out-of-state. She was his primary caregiver in her home for 10 months prior to the first move to a small AL with 5 residents. The first move was precipitated by her declining health and his hospitalization. He was discharged from the hospital to the first AL. She moved him 3 more times. All to AL homes with 5 or fewer residents. The second move was the result of his agitated behavior. The third move was the result of the FCG's desire to help him become more engaged. The final move was the result of *Tom* being evicted secondary to his behavior. He died 4 months later. *Jacque* was neither encouraged nor discouraged to visit by any of the staff at these homes. She initially visited daily after each move and after several months relaxed her visitation pattern to a minimum of 4 to 5 days each week.
2. A wife, *Nancy*, initially moved with her husband, *John*, to an AL home with more than 11 residents. The AL was designed with an aging-in-place concept and was conceived as their last move. The initial move was precipitated by *John's* diagnosis and the realization that as things progressed *Nancy* would not be able to manage his care on her own. The second move occurred 8 weeks prior to the interviews. She chose an AL with 5 residents that was highly recommended by friends and family. He died 6 weeks after this move. The second move was precipitated by

wandering behaviors and a violent outburst. *Nancy* felt welcome, but was neither encouraged nor discouraged to visit by the AL staff. He died 6 weeks after the second move and was hospitalized 3 times during the 6 week period. The AL staff called either *Nancy* or her daughter frequently for assistance with *John's* agitation. *Nancy* visited from lunch time into the evening hours and her daughter visited every morning.

3. A daughter, *Barbara*, was a long distance caregiver. She moved her mother, *Jane* to an AL home with more than 11 residents. The move was precipitated by a fall. *Jane's* disease progressed rapidly and she died 2 months after the move. Although *Barbara* and her family felt welcome, they were neither encouraged nor discouraged to visit by the AL staff. Either *Barbara* or a family member visited on a daily basis with *Barbara* maintaining daily telephonic contact for as long as her mother was able to communicate.
4. A daughter, *Maryann*, was the primary caregiver for her father, *Jack*. She moved him to an AL home with more than 11 residents 9 months prior to the interview. The AL was located closer to her than his home, which had been 50 miles away. She had employed multiple strategies to keep him at home including episodic stays with her; remodeling his home to accommodate the occupational therapist's recommendations for railings, grab bars, etc.; and hiring full-time caregivers. The move was precipitated by a significant fall that nearly cost him his life. Although *Maryann* felt welcome, and was neither encouraged nor discouraged from visiting, the

AL staff contacted her frequently to assist with *Jack's* agitation. As a result, *Maryann* initially visited before and after work every day. Over time, her visitation pattern has evolved from twice daily visits to approximately 3 days each week.

5. A son, *Michael*, was both a long distance caregiver and the primary caregiver for his mother, *Karen*. He was accompanied to the interview by his wife, *Jenny*, who was his primary source of support. He moved *Karen* 4 years ago to the AL she had chosen in the early stages of her disease. It had more than 11 residents. *Michael* had wanted to move her the 750 miles to be closer to him, but realized this would be too disruptive for her. Additionally, she would not have been able to bring her cats with her, which would have been a huge blow to her and so he moved her to the AL she had chosen in her home town. The move was precipitated by the fact that she lived in a condominium complex and would frequently forget to turn off the stove, would place flammables next to the electric heater, or put the stopper in the sink and forget to turn off the water. She would not allow anyone to live with her. Consequently, he feared that she would harm herself or her neighbors. This provided the impetus for the move. He too felt welcome at the AL and was neither encouraged nor discouraged from visiting. *Michael* visited weekly during the first few months. This pattern evolved into a trip at least every 3 months with daily telephonic contact.

6. A daughter, *Diane*, was the primary caregiver for her father, *Henry*. After trying to take care of him at her home as well as bring in informal caregivers to his home, she moved *Henry* into an AL with more than 11 residents 2 years ago. The move was precipitated by his wandering, falls, and declining health. They had lost *Diane's* mother, 30 years before and she had "been there" for him ever since. By her own admission, *Henry's* needs almost always took precedence over her own. She felt welcome at the AL and was neither encouraged nor discouraged from visiting. For the first 3 months *Diane* stayed with him around the clock. This evolved into daily visits for shorter time periods. After 6 months she began taking an occasional week away with her husband. She continued to maintain daily contact via telephone while away and hired a caregiver to be with *Henry* several hours a day during her absence.
7. A daughter, *Theresa*, was the primary caregiver for her mother, *Kate*. *Theresa* moved *Kate* from out-of-state to live with her six years ago. *Theresa* provided *Kate's* care until *Kate's* wandering put her at risk for bodily harm and *Theresa's* energy was fully expended. She moved her mother 2 years ago into an AL with 5 residents that was similar in design to her own home. She never told her mother the move was permanent and both hoped that she would return home. *Theresa* initially felt neither encouraged nor discouraged from visiting, but shortly into the stay was discouraged from taking her mother to church in the evenings because the AL conveyed it was causing *Kate* to become agitated when she returned

to the AL. *Kate* died 2 years after moving. Initially, *Theresa* visited daily.

The visitation pattern evolved to 2 to 3 times each week.

Additional description of the sample is included in Tables 1 and 2.

Table 1. Demographics

Dyad	Pseudonym	Relationship	Ages	Education	Relationship Quality
1	Jacque	Daughter	61	1 year college	Close
2	Tom	Father	87	HS Graduate	Close
	Nancy	Wife	77	Diploma Program	
3	John	Husband	81	BA	Close
	Barbara	Daughter	56	PhD	
4	Jane	Mother	85	AA	Extremely Close
	Maryann	Daughter	42	BA	
5	Jack	Father	71	HS and vocational certificate	Close "somewhere in between"
	Michael	Son	53	BA	
	Jenny	Daughter-in-law	51	BS	
6	Karen	Mother	77	BA and all but thesis of master's	Extremely close
	Diane	Daughter	55	HS	
7	Henry	Father	86	8 th grade	Extremely close
	Theresa	Daughter	50	HS	
	Kate	Mother	94	8 th grade	

Table 2. Assisted Living Facility

Dyad	Distance From FCG	Number of Beds	Number of PWD	Payment Source	Visitation Guideline	Time Since Move
1	4 miles 2 miles 10 miles 3 miles	5 5 5 5	5 5 5 5	GR/self-pay	Open	2 years 23 months 1 year 5 months
2	Together 2 miles	50 5	70% 5	MCD Waiver	Open	2 years 8 weeks
3	12 hour flight	45	50%	Self	Open	4 months
4	5 minutes	48	100% on his unit	LTC Insurance self-pay	Open	9 months
5	750 miles	48	85%	Self-pay	Open	4 years
6	6 miles	54	100%	MCD Waiver	Open	2 years
7	2 blocks	5	100%	MCD Waiver	Limited	2 years

These FCGs described the transition as a “journey” without end that began with arriving at the decision to move the person with dementia into assisted living and continued until death and beyond. Rarely, did FCGs describe the move as easy, but rather as one of the hardest things they ever had to do. They likened the experience to giving birth, only harder. For the majority of these participants there was no direction regarding visitation leaving them on their own to determine what worked best. It was akin to being on a river that was flowing through a series of rapids toward a pool of calmness. The FCG was paddling hard trying to find a route to make it through the rapids without harming

themselves or the PWD in the canoe with them. But, rather than reaching the pool of calmness, the FCG would turn around the bend and the river would suddenly change course into more turbulent waters with the hope of yet another pool of calmness ahead.

Aim #1 and Its Associated Findings

Aim #1: Describe the FCG's experience when a person with dementia transitions to assisted living from home or another assisted living environment.

The themes developed from the participants' descriptions pertaining to the first aim included:

1. There was no longer a choice
 - a. It wasn't safe anymore
 - b. FCG Exhaustion
2. Choosing the Home
 - a. Be safe...
 - b. Selecting from less than ideal options
3. The move
 - a. A day not forgotten
 - b. "It's going to shorten his life"
 - c. Whatever works
 - i. Easing the transition through connection
 - ii. To tell or not to tell
 - iii. Doing whatever works

4. The emotion of it all
 - a. The emotions
 - b. Managing the emotions
 - i. Monitoring the care
 - ii. Doing something tangible
 - iii. The back-up plan
 - iv. The support network
5. The transition
 - a. The beginning is “hell”
 - b. Settling in

The following discussion uses the descriptions of the family caregivers to elucidate these themes.

There was no longer a choice. Family caregivers described the transition as beginning with the impetus for the decision to move the PWD to AL. In all cases, the moves were precipitated by crises either for the FCG or involving the person with dementia. The decision to move was seen as the only option left to them. Two distinct, but overlapping reasons prompted the move to assisted living: concerns for safety and caregiver exhaustion.

It wasn't safe anymore. Safety was the driving force behind every FCG's decision to move, whether it was the safety of the PWD or those around them. For many family caregivers, safety trumped the PWD's desire to remain in their current living situation. Most FCGs had already exhausted other options including moving the PWD into their homes, hiring home care agencies to keep the PWD

in their own home, or allowing the PWD to be on their own until they reached the point where they became a threat either to themselves or others. *Theresa* described coming to the decision,

I wanted to take her everywhere with me, but I couldn't take her everywhere, especially in the wintertime. It was just too much. I couldn't live with her walking out in the wintertime. I hid shoes. I hid slippers. I hid coats. I hid everything. She'd walk out in the snow with her socks on.

Michael and *Jenny*, who tried to keep *Karen* in her own home, described his mother as being:

...very resistant. She wasn't ready. She wanted to live on her own, she felt like she could. She really didn't believe there was a problem... She had a two-bedroom condo, but she wouldn't allow someone to come live with her...My fear at the time was she shouldn't be living on her own, that she was going to hurt herself and possibly other people around her when she left the stove on or walked away from, and I mean you start to think about how she might burn the place down, with herself in it, along with all these other [trails off lost in the memory for a moment]

Most tried to keep the PWD where they were. Most had endured multiple worrisome incidents prior to the final decision to move. For *Maryann*, "The [last] fall changed everything." Nobody expected him to survive. "I thought to myself, how many more red flags do you need?" It was evident that the FCGs struggled to identify when the safety concerns were of a magnitude that would warrant the move to AL and override the PWDs' preferences to remain in their homes.

Family caregiver exhaustion. FCGs who had moved their parent in with them described being utterly exhausted. Exhaustion, then coupled with safety, played a role in the final decision to move. *Theresa* shared:

I think I was laying upstairs in bed. And I said, God, I don't want to take my mother and put her any place, but I can't do this anymore. I'm losing myself. I'm losing who I [pause], do you want me to live? She'd be up to

2:00 or 3:00 [in the morning]. I'm back up at 6:30 in the morning with my kids.

Theresa described having nothing left. She said that was the day she walked up the street, knocked on the door of the AL she had chosen and asked if they had a room.

Maryann described it this way:

The ability to reason, the common sense, all of that somewhat dissipated at night...I slept with one eye open at nights and then trying to work in the daytime, it was really taking a toll. But just hearing him get up, because we've got wood floors, we'd go in there and say, "Dad, do you need a drink of water? What can I do? Can I get you something? How are you doing?" At 2:00 in the morning right, "Oh, I'm ready to get up". There was one night I was so exhausted, I just pleaded with him, "Dad, I'm so tired, it's only 2:00 in the morning. Can we try and rest. Where do you want me to sleep? He's standing in front of the bed. "Right there behind you is the bed". He turns around, "why do you want me to lay down in a bus station?"

Continuing in their current situations was affecting their families, themselves, and the PWDs. Caregivers felt they "had no other choice" (*Theresa*), "something had to change" (*Jacque*).

Choosing the home. Choosing the home was the next challenge the FCGs faced. Wait lists, payment sources and AL availability all played major roles in the decision to choose a particular home. Most family caregivers put their names on multiple lists in hopes of being accepted. Others tried to wait so the PWD could move into the home of their choice. There were a myriad of questions FCGs asked themselves as they not only tried to respect what was important to the PWD, but also meet their own needs. Was it close to family? Did they take pets? Was there medical available? Was it close to the PWD's social networks? What was the reputation? Would the PWD like it? Caregivers had many

questions, but all agreed that what they wanted most was for their family member to “be safe, be happy and be well-cared for”.

Be safe... Some of the FCGs were clear about what they wanted. “I wanted him safe and happy” (*Diane*). They searched for homes that would meet these criteria. Hours were spent contacting ALs on the State list in hopes they would find a place that would keep the PWD “safe and happy”. Others relied on the recommendation of other people who had knowledge of AL homes to meet these criteria. Others compromised between their needs and the needs of the PWD.

Choosing from less than ideal options. Although FCGs had criteria including desired location of the PWD, availability in the home of choice, or acceptance of their funding source; the criterion could not always be met. FCGs then had to choose from less than ideal options. One long distance caregiver considered the impact of relocation and the need for his mother to have her cats nearby. Rather than moving her to a facility in his home town, which would have been easier for him both from a visitation standpoint and a financial standpoint as her home town was accessible only by boat or plane, he moved his mother to a facility where she could keep her cats, even though it meant he would have to travel long distances to visit.

The move at that point would have been way too disruptive for her, plus the fact that it’s our understanding that they [the home] would not allow for her to have her cats with her up here. And that was going to be a huge issue. Those cats were her whole life” (*Michael*). Others had other family members or friends of family who had been in the home and so they had first-hand experience.

My grandmother was in the home in the town we grew up in. My great-aunt was in the home in the town we grew up in. Other relatives have

been in that facility, and frankly it is, in my opinion, a pretty warm, welcoming, safe place, and I have felt pretty comfortable with the situation and with the people we're working with there (*Michael*).

Two FCGs moved the PWD multiple times until they found a place where they were happy:

I was so unhappy with that [the second] house. I actually went through the whole process of calling around trying to find another place for him and we were very....I was thrilled with this third house (*Jacque*)

Some caregivers evaluated multiple options before finally deciding on what they hoped was the perfect home. "I looked at little ones and big ones and this and that, and this and that and then must of driven the one I chose crazy. I'd go like six times a day, well, can I see that one, can I see that one (*Diane*)." The ultimate goal for all of these caregivers was for the PWD to be "safe", "happy", and "well-cared for".

The move. For the participants in this study the move left its mark. Few of them spent much time spontaneously setting the stage when describing the day. In fact, some of them never discussed the physical aspects of the move at all. But, all of them described how the PWD responded and how they felt.

A day not forgotten. Whether it had been 8 weeks or 4 years the FCG had vivid memories of the day of the move. They described it as filled with "unknowns", a lot of "second guessing". They asked themselves, "Was it selfish" (*Maryann*)? "Will they get appropriate care (*Maryann*)?" "Did I do it right (*Nancy*)?" "What had I done (*Diane*)?" "It was overwhelming (*Maryann*)."

They described the hardest thing as the PWD's reaction. *Jacque* stated, "[Dad] was convinced he could do everything...He didn't wanna go...It was

confusing” (*Jacque*). *Tom* called her repeatedly to come take him home. For *John*, he could only surmise that a catastrophic event had occurred for him to be living separately from his wife. “He asked if we were separated” (*Nancy*). *Barbara*, for whom the decision to move was “easy”, expressed concern that her mother would react in the same way her grandmother reacted when her mother moved her grandmother to AL. Consequently, when they had their conversation about the move, *Barbara* waited with trepidation for the reaction,

[We] had this conversation and she looked at me, and she just went, ‘Oh,’ in her – the way that she would say ‘oh’. And [I’m thinking], ‘Okay, if she does what her mom did, that would mean she would start crying’. But she didn’t. She just looked at me. And so she said, ‘So this is my home.’ And I go, ‘This is your home, now.’ She wasn’t happy (*Barbara*).

Maryann recalled, “[*Jack*] was so anticipatory he didn’t sleep the night before. I almost wish the caregiver had not even told him.” Diane cried as she shared *Henry’s* response. He said, “I don’t need this you know and I don’t understand why you would do something like this to me. You know I’ve always been there for you kids”. The following morning she received a call from the AL staff that *Henry* had had a heart attack. *Theresa* “bawled like a big baby.” *Michael*, who moved *Karen* four years ago, described it as “very difficult” and then waved the researcher off as the tears welled-up. He couldn’t address the question. It did not matter how much time had elapsed since the move, that day was remembered like it was yesterday.

It’s going to shorten his life. For those who had to make multiple moves, each move was filled with anticipatory fear not only of the PWD’s reaction but also of the effect it would have on his longevity and the time they had left

together. “It was going to take a year off his life (*Jacque*).” “He’ll – he’ll go downhill too fast (*Nancy*).” *Nancy* and *Jacque* both begged for rescission of the eviction. Both described feeling fortunate because despite a short quantity of life after the final move, they both felt they “could not have asked for better (*Jacque*).”

It was clear from these participants that the actual move left an indelible mark. Most continued to wonder whether they had done the right thing in making the decision to transition their family member to an assisted living environment.

Whatever works. All of the FCGs described the multiple strategies they employed to try to lessen the impact of the move for the PWD. They did not want the PWD to feel they had been abandoned and so they tried multiple approaches to maintain the PWDs’ sense of connection. They struggled with whether to tell or not to tell the PWD about the move before it happened. They tried multiple approaches to help ease the PWDs into their new environment once the move had happened. They did whatever it took to help the PWD during the move.

Easing the transition through connection. Each of the FCGs in this study described the measures they used to help the PWD feel connected. For some it was providing a cell phone, for others it was staying with them through the first few weeks of the move, whether that meant sleeping in a chair or staying on the floor. All of them called and physically visited. For those who had formal caregivers prior to the move, the FCG hired that person to remain involved for several months following the move. The majority took familiar objects that held

some meaning for the PWD...furniture, hats, a family reunion t-shirt, pictures, something the caregiver had made.

I had made her this doily that was purple and gold several years ago. I brought that. I had this one thing that I had come across for her that was like a mother's love, so I had brought that. I had made her this...lilac blanket that's fleece. And then I had then, on the underside of it, had put purple fleece because her favorite color was – is – was purple. And in the winter, last winter, when she would sometimes get up in the middle of the night, my niece would either find her sometimes on the sofa, you know curled up in the blanket, or my brother – because he would spend some nights with her – would find her in the morning on the sofa with the blanket. I brought that (*Barbara*).

Some chose homes that were similar in design to the homes the PWD knew: “it was small like my home...She had the exact same window at our house that her husband built for her. We had big huge picture windows all around the house and she sat there at the table. And she'd look out the window. So I mean it was very familiar” (*Theresa*). For those who had to make multiple moves, the “constant familiar” became the FCG because as the disease progressed the PWD recognized fewer and fewer of the material things. For those whose name the PWD no longer recalled, the personal connection remained:

She kept taking my hand and putting it up here to her heart when I was sitting down. She kept taking my hand and putting it up here. I was like, “Mother, I know that you're trying to tell me that you love me” (*Theresa*)

To tell or not to tell, making it easier. Some chose to let their relative know about the move in advance; others kept it a secret until they arrived at the facility because they thought it would be easier for the PWD. Prior to the move some FCGs involved the PWD in the decision about the move. “...we had conversations where he knew that was going to happen even before his fall when he had more clarity and he agreed to it.” For some, the PWD had chosen the

assisted living place before the cognitive changes affected decision-making. “She and her husband had put themselves on the list, and that was their wish at the time, that they move to the home.” Others talked about the move or toured AL homes to find one the PWD liked. Some FCGs chose not to tell the PWD about the impending move. “If I’d said, Mother, I’m not gonna bring you back here to the house. You’re gonna have to stay here because I can’t take care of you anymore. It’s just too – too much for me. She wouldn’t have been able to comprehend that” (*Theresa*). *Nancy* had discovered over time that “if I told him things that were coming, he would dwell on it and talk about it and question it. And – and so we didn’t tell.” Whichever approach the FCG took, the motivation they described was to make the move easier for the PWD and, though unspoken, perhaps for themselves as well.

Doing whatever works. Regardless of whether the PWD had been included in the decision or not, none of them were happy to leave their homes. FCGs would try to ease the impact of the move through a variety of different approaches. One commonly used strategy was to focus on the positives. “You’ll have lots more visitors” (*Barbara*). “You don’t have to worry about cooking” (*Maryann*). “You’ve got your own room” (*Theresa*). One FCG described it as, “You know you just try to make – find something good” (*Diane*). Some used cajoling, being frank, agreeing, distracting, deflecting, some enlisted other family members:

When we first got to the ALF, my dad idolizes my husband, and my dad wanted no part of this. I had to say, dad you know what, my husband hunted this place for you. He wanted it perfect for you. ‘He did?’ Yes, he did and you know he checked around a lot of places and felt you’d be safe

here, and look you have this really nice view. So it got a little better when my husband had done all that for him (*Diane*).

They continued to try different approaches until they discovered something that worked, even if it only lasted a little while.

The emotion of it all. For the majority of family caregivers the decision to move the PWD into assisted living was not described as an easy choice, but even when it was, it was surrounded by a “gamut of emotions” (*Maryann*). All FCGs described different strategies they used to help manage the emotion of it all. The strategies ranged from monitoring the care, to doing something tangible; to having back-up plans in the event the first move didn’t go well; to surrounding the PWD with things they had given them in hopes it would keep the PWD from forgetting them; and activating their network of friends, family, and formal caregivers.

The emotions. Most of the FCGs who participated in this study described an array of hopes and fears surrounding the move. Some weren’t sure that they had any hope left. Most expressed that their greatest hope was that the PWD would get better or the FCG would get better and the PWD could come back home. In reality, the caregivers cognitively knew this wasn’t going to happen, but it seemed important to hope for it nonetheless. Other hopes focused on being “comfortable” (*Jacque*), “that he would sleep, he would eat” (*Nancy*), she would be “safe and comfortable in the end” (*Barbara*), “We would see him more” (*Maryann*), and that the PWD would “be a little more engaged” (*Diane*). It was difficult to discern whether these hopes were grounded in realistic expectations

or whether they served to ease the pain of being responsible for the AL placement decision.

All, but one of the participants, expressed fears. The person who was free of fear described that she felt free of fear “because [she] knew it [the move] was for the best”. The others feared the “worst case scenario...possible decline to the point where they...die”. For some “everything was my worst fear, my decisions were not just affecting me, they were affecting someone else.” And yet one caregiver thought it, but didn’t speak it until the interview, her worst fear was “that they might not be able to keep him.”

Family caregivers describe a “gamut of emotions” from “relief”, to “sadness”, to “guilt”, to indescribable raw emotion. Some considered the move to be easy. But, overall they described it as “hard”, “very difficult”, “felt like a betrayal”, “so much hurt and emotional anxiety”. Rarely, did they regret their decisions, but it was “stress at lots of levels”. For *Jacque* and *Tom*, “it was hard. It was tough, but it was also a relief to know I could be sick”. “The hardest thing was he didn’t want to go. He would call on his cell phone and say: “You gotta get me outta here. You gotta get me outta here. You gotta come get me.” I’d pick him up, have him for a few hours, drop him off and then he’d be calling on the phone, “You gotta come get me. I can’t stand it here.” So, it was very difficult, especially at the beginning. For one FCG and PWD, the first move was easy. They had moved frequently throughout their marriage and moving into the first assisted living was another step in “home is wherever you are” (*Nancy*). But, with the second move the FCG didn’t know whether or not she had simply “lost hope by

then" (*Nancy*). "He thought we were separating" (*Nancy*). For another FCG "it was easy" because she no longer "had to worry" (*Barbara*). For *MaryAnn* and *Jack*, it was a "gambit of emotions":

I wasn't regretting the decision, it was just the actual move had so many emotions tied to it because it was that day that I promised my dad and myself that would happen actually... And we had conversation where he knew that was going to happen even before his fall when he had more clarity and he agreed to it. We had lots of communication about it. But, it's just when that day actually comes it's just so many emotions that you're not even sure you're ready to deal with and what do you do with them now that they're here?...May be some relief knowing that he was only 5 minutes away (*Maryann*)

For *Michael*, *Jenny* and *Karen* "it's been a struggle":

...there's just a lot of emotional turmoil for everybody involved, and so like I said I got to the point where I wasn't going to the town we grew up in unless my wife went with me, because I needed the moral support if nothing else. I mean, I was going freaking crazy... it makes you feel uncomfortable because maybe you feel a little guilty and you know all those other, you know what I'm saying? So it's, you know, you just replay this thing on an ongoing basis, and it just becomes very wearing and you've got to really watch, kind of look out for yourself in terms of all the emotions involved and all that sort of thing, because it just becomes kind of a grind and it starts to eat at you (*Michael*).

For some FCGs it was a combination of guilt, feelings of betrayal, and second guessing.

He had just signed that no resuscitation and it was like wholly-smolly, what have I done?...You never mean to make it about you, but it is a factor too. It's like he would have been real happy and safe in his bed, if I'd left him alone. No, I got to take him to a new place and he has a heart attack, that's nuts...He just didn't understand why we would betray him like that. Why we couldn't just make up, let him go home, we'll forget the whole thing. And why would your own children do something like that to you" (*Diane*).

And for others the "guilt was larger than the fact I couldn't take care of her":

here's this person that has raised you and brought you to the place that you're at. And now they're needing you to take care of them and you're incapable of doing it? [tears] What is that?

...she basically just said to me, I'm feeling like I have a family that I can be with and I'm not with them. And that's kind of what I – and I – and that day was like a terrible day for me. I – I – I tried not to cry when I was there because I understood what she was saying. But I didn't want her to know that I understood what she was saying. I was trying to stay full – you know, but I got in my car and I just sat and I wept [tears coming] (*Theresa*).

But it wasn't all guilt and sadness, she also describes times of relief in knowing *Kate* was well care for, knowing “that they were keeping her clean” and “fed”.

Managing the emotions. For these FCGs the transition was filled with emotion. They needed to find ways of managing the emotion so they could continue to be present for the PWD. They used a collection of different approaches to cope with the impact. Just as they tried to provide the PWD with a sense of connection so the PWD wouldn't feel abandoned, they themselves needed to maintain a sense of connection.

Monitoring the care. Caregivers described the importance of just “being there and seeing how he was adjusting” (*Diane*). This, in general, was described as being sure “they” were taking care of the PWD properly. “I'm walking in, making sure, ‘Are you taking care of her right?’” (*Theresa*). They felt they were watching out for the PWD and for some this helped to relieve part of the guilt they felt about having to make the decision to move the PWD.

Doing something tangible. *Karen* described the need to do something physically as, “...just feeling like if I could physically do some things maybe it would help me feel better”. Another FCG described it as a way to stay connected,

“I did her med sets... it was a just – it was staying connected to her. I wasn’t really, really wanting to relinquish so much so that I would – it’s just like you just forget about that you have a mother around the corner”(Theresa).

The back-up plan. For some caregivers, planning for contingencies provided a degree of comfort. “If the assisted living thing really was not working and we saw huge declines in my dad, then we’d have other options. We could always go back out; there was a place open, it was going to be close to us” (Maryann).

The support network. All the family caregivers described the need for friends and family whether it was the church family, long-time friends, brothers, sisters, spouses or children. All of them described the need for “moral support”. All of them needed someone who understood. For one FCG who found the emotional aspects of the forced move overwhelming, he and his wife incorporated a professional to actually help with the immediate transition period. “When you can hire somebody, it’s their job and they just, they do their job, in a caring, compassionate, but somewhat detached way, so they can get the job done”(Jenny). “Because I think she was able to kind of step back from the situation and deal with it head on, rather than get caught up in – the emotion of it” (Michael).

The transition. For most people terms such as “settling in” and “transition” connote a shorter time frame with a beginning and an end. With rare exception, what these family caregivers described was a transition without end.

They describe more challenging times in the beginning, but when asked how long it took the PWD to “settle in”, 5 of the 7 responded they “never did”.

The beginning “is hell”. Family caregivers described the first couple weeks as “hell”. PWDs pleaded to return home. The PWDs sleep patterns changed. For some they never slept through the night again, some only slept for 15 minutes at a time. Some became agitated. Some became despondent. Many FCGs slept in chairs or on the floor to reassure the PWD. Many came morning and night to check on them.

Settling-in. The family caregivers’ descriptions of the point where they felt the PWD “settled-in” varied greatly between 4 days and never. “After we had the conversation on that Wednesday, you know, I knew she wasn’t happy with me...but by Saturday she was smiling.” *Karen* stated, “I would say that we’re almost to the one year mark now so I feel like any adjustment period has come and gone at this point in time. I feel like we’ve been very lucky in that regard.” While others on the opposite end of the spectrum described it as never settled. *Nancy* described it as “before the move he always slept, after the move he never slept again”. *Theresa*, who was two years from the move, was asked when her mother felt at home, and she responded, “Never, never. She – even to the last, she would say – I would get ready to go. She says, ‘Oh, are we going? Am I coming with you?’ and grab her purse. I never got used to it.” For the caregiver furthest from the move, 4 years, he describes the transition as ...”a struggle ever since...right now she’s waiting for us to come back from our trip so we can plot

on how to get her out of there together, because she feels she's going crazy there." For some family caregivers it is a transition without end.

For these participants, the transition of a PWD to an assisted living was described as one of the hardest things they had ever done, but they didn't feel they had a choice. For some it was easier because they no longer had to worry. In every instance safety was the driving force in the decision process. It included not only the safety of the PWD, but the safety of those around them. Regardless of time or reason, the memory of the move was ingrained in their brains. They employed a variety of strategies to ease the transition not only for the PWD, but for themselves. All sought to remain connected to the person with dementia. Doing things and surrounding the PWD with the familiar became paramount. The transition involved a variety of emotions including relief, guilt, sadness, and second guessing. The most striking finding in the majority of their descriptions, however, was the idea that the transition never ends; neither the PWD nor the FCG ever "settles-in".

Aim #2 and Its Associated Findings

Aim #2: Describe how the FCG's understanding of the family visitation recommendations of the assisted living influence FCG's perception of, and reactions to the admission transition.

According to the visitation policies outlined in the resident rental agreements, the official visiting hours were between 10 in the morning and 7 in the evening. None of the facilities enforced these hours. The majority of family caregivers in this sample felt neither encouraged nor discouraged from visiting

and described the perceived visitation guideline as open—that it was never really talked about. They could come whenever they wanted. They could stay overnight, if they wanted. One described feeling encouraged, but on clarification classified it as neither encouraged nor discouraged, she felt welcome any time. Another was discouraged from taking her mother to church regularly because it was hard to settle her after the FCG left. The themes developed from the participants' descriptions pertaining to the second aim include:

- Always on call: Ever vigilant;
- Caregiving continues:
- Staying connected;
- It takes a village;
- In time visitation evolves; and,
- Finding peace: The gift.

Always on call: Ever vigilant. This group of FCGs, who described their relationship with the person with dementia as close or somewhat close, described their visitation schedule during the transition as “always available”. In one instance, *Jacque* provided her father with a cell phone so he could call whenever he needed. She “went over after work, Sundays, literally there were not 4 or 5 days in a row [she] wouldn’t see him” (*Jacque*). In the beginning, she brought him home often. The home told me, “the only time he’s happy is when you visit or pick him up” (*Jacque*). For the first few days *Nancy* stayed around the clock with *John* and slept in the chair until her daughter intervened. And while she reduced the time she spent in the facility, she continued to go every day. Her

daughter would stay with him at night on an episodic basis. The home called whenever they needed help and either *Nancy* or her daughter would respond. This gave them a sense that they were helping with his adjustment. In fact, they wanted to be as responsive to the facility staff as possible as they were already experiencing the consequences of a forced relocation and *Nancy* feared the home wouldn't be able to keep him if he didn't settle in.

Maryann initially went over "every day before work, every day after work". She remained "only a phone call away" and visited frequently as did *Michael* and *Jenny*.

When *Diane* first started going, she was "going every day and staying". She slept on the floor. This lasted for about 3 months until she "had to choose between [her] work responsibilities and [her] father and so they had to change." "I still went every day, but only for a window."

Theresa spent every night the first two weeks, sleeping in a chair in her room. All of the FCGs reported that they responded whenever they were called. As time progressed some of the FCGs began to relax their visitation schedule. Some reported that they varied the times they visited as they wanted to be sure the home "wasn't cleaning [the PWD] up for show".

Theresa was the only caregiver in the sample who was discouraged from visiting during specific times after the initial transition. She was discouraged from taking her mom to church on Friday night. She describes her reaction, "it was really hard, it felt like I was giving up a part of her...We had always gone to church on Friday night since she moved here." "They explained I was causing my

mother more harm than help.” She would become agitated and want to go home with *Theresa*. “It would take her hours to settle down. It was disruptive. I stopped.”

Caregiving continues: Staying connected. The family caregivers in this study instituted a number of different strategies in order to stay connected, one of which was to continue caregiving. This was true whether the caregiver was providing care from a distance or whether they were available locally. Caregiving duties involved taking the PWD to their appointments, managing their medications and filling the med sets, administering insulin, directing care, monitoring the care given, addressing issues as they arose, monitoring food intake, daily exercise, and being sure any recommendations from health care providers were carried out. Although there were options to have medications delivered or to have home health nurses monitor the PWD and to administer insulin injections; all of these family caregivers continued their role. “It kept me connected. It kept me from forgetting...”

“It takes a village”. Whether it was immediate family, church family, friends, or day services, none of these family caregivers reported that they neither could nor wanted to do it alone. Some like *Jacque, Nancy, Maryann, Barbara* and *Diane* had help from their families. For *Nancy*, her daughter would take the calls from the home at night, “they would call her and she’d go”. *Michael* and *Maryann* hired a formal caregiver to help. Friend networks were incredibly important for the caregivers whose families were not involved. Eliciting support

from others not only provided much needed respite for the family caregiver, but also became motivated by the positive effect they noticed on the PWD:

you're not the end that'll be all, and he doesn't need you, he needs a village. He needs a lot of different people exposing him to different conversation and he thrives on that. And you know I can smother him, I think, I think that it was good that he sort of pushed me out. [He was saying] I can do this. It's not the way you want me to do it, but I can do this, and he's right.

Barbara and *Maryann* noticed that when the children visited, the PWD was "much brighter". *Maryann* recalled, "when my kids were home for the summer, we saw him and he was so excited! He doesn't do that when I come in." *Barbara* noticed the transformation not only with her mother, but in the care facility in general:

We all knew that my mother loved her grandchildren and great-grandchildren. They always brightened her day. The staff let us know that and did not mind if there was a 3 year old great-grandchild running around with a book or two for great-grandmother to look at with him and for my nephew or me to read to the both of them. It was as if her having her young great-grandchildren around made not only her happier, but other residents who did not have as many visitors and especially the young ones. I could visit my mother anytime, but the laugh of great-grandchildren seemed, be it one or a few, to make the atmosphere so much brighter within the care facility.

In time, visitation evolves. For all the family caregivers their visitation patterns evolved over time. Most of them visited frequently, if not daily, in the beginning. As time elapsed, the majority of caregivers relaxed their visitation schedules. It occurred in part because they felt more comfortable with the formal caregivers at the assisted living, they could trust their loved one would be well-cared for; in part because they felt they had to take care of themselves; and in part because they realized it was also good for the person with dementia. *Diane*

found as she became more comfortable she was able to relax her visitation schedule and take some time for herself and her family:

[My visiting is] much more relaxed. I've even been to California a couple of times. The first part of this I wouldn't have considered it. I don't feel frightened. I mean I just know his caregivers now, so I don't feel terribly frightened to leave him alone with nobody going in to make sure that he's fed or [pause] do I think they do 100 percent job? No, but that's who I am. You know it's like I'm nitpicking from the outside. They all function really well if I just leave the situation alone (*Diane*).

For some caregivers, it was about finding balance and taking care of themselves. *Michael* described it as:

...it was like having a second job. And then we were, I was back and forth for quite a while, and then I got to a point where for myself it was extremely difficult to go down there and deal with this situation...you've got to really watch, kind of look out for yourself in terms of all the emotions involved and all that sort of thing... So I'll call and talk to Mom but often I'll come home and say to my wife, "would you call my mom and talk to her?" [pause] Because I can't.

For the PWD relaxing the intensity of the visitation schedule, in some instances, allowed them to get to know their caregivers and begin to become part of the community

We had an annual buying group meeting, it was a mandatory attendance and that's usually in March and it was the first time I had to leave him. And probably the best thing that happened to us because he had to get to know his caregivers and he found that they were rather nice people...Now when I call and tell him something has come up and I won't be able to come over, he says, "don't worry for me, I'm never alone...I'll be just fine. And I think in the background he's going, 'oh, thank God I get a day off!'" (*Diane*)

Finding peace: The gift. These family caregivers recognized many rewards in being able to be with the PWD and to visit when they wanted. For some they were able to become "close and we got to share a lot of things" (*Jacque*). For others it was learning to find hope in unexpected places. "Hope is

going the night before last and listening to him laugh like a little kid at silly little videos on TV”(Maryann). They described many gifts: the peace of “being present for him” (Maryann); learning “patience” (Michael); discovering that “time eases pain, time’s a gift” (Diane); and

The things that I learned from her, because she was still teaching me: love, patience, long suffering, gentleness, goodness, faith. God allowed me to learn them. I needed the grace and the patience to learn (Theresa).

Summary

The FCGs who participated in this study all moved the PWD to AL from home or another AL. All described the need to keep the PWD, or the people around them, safe from harm as the driving force behind the decision to move the PWD into assisted living. For those who had been caring for the PWD at home (3), exhaustion was coupled with safety to create the driving force. None of the FCGs made this decision lightly and all tried various strategies to avoid or delay the move. The decision was made when they felt they no longer had a choice. The choice of AL was based on availability, but the home was also chosen with care considering design, proximity to friends and families, PWD preference, and reputation of the home. For 6 of the 7 FCGs the decision to move was hard, but for all of them the actual move was filled with emotional turmoil regardless of the degree of planning and the care employed in selecting the home. One caregiver likened it to giving birth, only worse.

For 1 of the 7, the decision to move was “easy” because she “knew it was the right thing to do” (Barbara). Because of her professional training, this FCG was involved in the process of guiding the family through making decisions in the

care of her mother and thus identified herself as the intimately involved in her mother's care. She lived a significant distance from her mother and was only physically present during the weeks surrounding the actual move. For her, it might be concluded that the move was easier because she was able to clinically determine it to be the "best" course of action and operate on "just the facts". Her visitation after the move was performed telephonically allowing for a degree of separation not experienced by the remaining participants. For the FCG, her description of the transition varied from the remainder of participants in this study in that she never second guessed her decision.

For all but the first move experienced by the spousal FCG, the PWD was classified at stage 4 or higher on the global deterioration scale. The first move of the married couple occurred during stage 1-2 for the PWD and they moved together. This move represented just one in a series of moves over the course of their marriage. They had always considered home to be where they were together and consequently did not find the first move to AL difficult at all.

All FCGs had hopes and fears. Some hoped the move was only temporary and that somehow the PWD would be able to return home, others hoped only that the PWD would be safe, comfortable, and well cared for. Other fears paled in comparison to the fear of rapid decline and death and worry about the possibility of yet another move.

FCGs in this study employed multiple strategies to lessen the impact of the move for the PWD. They did not want the PWD to feel they had been abandoned and so they attempted multiple approaches to maintain the PWD's

sense of connection. They struggled with whether they should tell or not tell about the move before it happened. They tried multiple strategies to help the PWD ease into their new environment once the move occurred. They did whatever it took to help the PWD during the move. They tried focusing on the positives; they tried to make the environment familiar; they tried cajoling, being frank, agreeing distracting, deflecting and using other family members the PWD trusted.

Despite preparation or readiness for the move, FCGs found themselves facing emotions they were unprepared to handle. Much of that was predicated on the response of the PWD to the move. Fearful that her mother would react to the news in the same way her grandmother had reacted when she was moved to a facility, even the FCG who found the decision to move “easy” waited with trepidation when she informed her mother that she wouldn’t be returning from the rehabilitation center to her home. Fortunately, for this caregiver, her mother did not cry, but stoically acquiesced. Although, the FCG knew her mother was not happy, her mother’s response emotional response may have provided a level of comfort for the FCG when she had to return home a few days later.

As these FCGs tried to manage the emotions surrounding the move they enlisted the support of friends, family, and professionals. They tried to maintain a sense of connection to the PWD as they monitored the care the PWD received and did something tangible for the PWD (med sets, laundry, provider visits, coordinating with facility staff).

For most people and in previous studies the term transition or settling in connote shorter time periods with a beginning and an end. But, for these FCGs, what they described was a transition that never ends.

During the immediate transition none of the FCGs were either encouraged or discouraged from visiting the PWD and all felt welcome. Despite written guidelines from the AL to the contrary, all caregivers were allowed to come and go as they pleased with almost half of them choosing to spend the nights to help the PWD settle-in. FCGs initially visited daily. As their level of comfort increased with the formal caregivers they began to relax their visitation schedules. For some this was a matter of weeks, for others it was months. Despite an increased level of comfort the FCGs remained “always on call” to respond in the event the PWD became agitated or a crisis occurred. Maintaining a connection with the PWD was paramount for these FCGs and they sought to do this through phone calls, physical visitation, and continued caregiving. This occurred regardless of whether they were in the same town as the PWD or whether they were providing care from a distance. For the caregiver who was discouraged from taking her mother to church in the evenings because her mother became agitated after she returned to the AL home, she felt like she gave up yet another part of mother and searched for other ways to stay connected. Because of the way it was presented by the home’s administrator this FCG framed no longer taking her mother to church in the evenings as doing what was best for her mother, but at great personal sacrifice. As time elapsed from the initial move, the emotion of the move

remained ingrained the FCGs memories, but time also helped caregivers to recognize the gifts that caring for the PWD provided.

Chapter 5: Discussion

Introduction

The purpose of this study was to describe the family caregivers' (FCGs) experience when a person with dementia (PWD) transitions to assisted living (AL) and how the FCGs' understanding of family visitation recommendations influence the FCGs' perceptions of, and reactions to, the admission transition. Results of this investigation support prior findings related to the process of transition, predictors of moving a PWD, continuation of caregiving after moving to AL, and factors that contribute visitation frequency. This adds to the credibility of these findings. The findings of this study also expand our thinking regarding visitation and transition. The focus of this discussion is to address the most salient findings and examine their implication for theory, practice and research.

Implications for Theory, Practice, and Research

Transition. Prior studies indicate that relocation is a dynamic process for both the cognitively intact and cognitively impaired individuals (Bramble, Moyle, & McAllister, 2009; Lee, 1997; Liken, 1998; Liken, 2001; Paun & Faran, 2011; Thomasma, Yeaworth, & McCabe, 1990; Victor, 1992). In any relocation, the phases for cognitively intact individuals are purported to last 1-2 months (Brooke, 1988; S. A. Wilson, 1997). For individuals who are cognitively impaired, it is posited this process could last up to 12 months (MacDonald, Philpot, & Briggs, 2004). Based on the literature, this study was designed to capture FCGs who had completed the three phases of adjustment: the overwhelmed phase, the

adjustment phase, and initial acceptance (Brooke, 1988; S. A. Wilson, 1997).

Secondary to recruitment challenges the decision was made to remove the “time since the move” inclusion criteria and the resulting serendipitous discovery has significant implications for theory, practice and research.

Theoretical implications. Existing transition frameworks commonly used in nursing such as Schumacher and Meleis’ (1994) conceptual framework examine transition from an individual perspective and posit that a completed transition occurs when stabilization in a new situation is achieved. For most FCGs in this study, the upheaval never really subsided, even years after the initial move. Stabilization and a new normal never seemed to evolve and the FCGs lacked closure and acceptance. For these FCGs their ability to transition appeared to be predicated on the ability of the PWD to complete the adjustment phase and achieve initial acceptance (Brooke, 1988; S. A. Wilson, 1997). They did not follow a linear progression, but instead vacillated between the phases proposed by Wilson (1997) and Brooke (1988). This offers an opportunity to re-conceptualize transition in this population as a dynamic interdependent process rather than an individual one. Given the fluidity of the dementia progression it may be that transition as we currently think of it only occurs at the conclusion of the dementia process and the transition to the AL may actually be a culmination of many small transitions. The results of this study provide insight into the effect of dyadic interaction when transitioning to AL.

Clinical implications. If, in fact, the FCG impacts the PWD and the PWD impacts the FCG as found through this investigation, interventions may be

developed to target behaviors that either support or undermine acceptance for the dyad. For example, if the FCG is a continual presence after the move might this prevent the PWD from forming relationships with new formal caregivers and other residents thereby undermining the PWD's adjustment to the AL? Then, as this study implies, if the PWD is unable to settle the FCG is unable to settle and they both remain in the overwhelmed phase. In this situation, interventions may be developed to help the FCG find a balance between continuous and intermittent presence that would meet the needs of both members of the dyad. This example speaks to the importance of shifting the approach of dementia care to one that is family centered rather than patient centered.

Further, using the idea of a dyadic interactive approach and incomplete transition, clinical interventions might focus on the meaning of the move. For the FCG the move to AL may represent not having to worry about the PWD harming themselves or others and provide a sense of relief. For the PWD, the move may represent loss of a familiar home, neighborhood, or friends and create a significant source of distress (Digby, Moss, & Bloomer, 2012; Svanstrom & Dahlberg, 2004; R. S. Wilson et al., 2007). This may in turn, as in this study, contribute to feelings of distress for the FCG. Therefore, development of interventions that would support the FCG's relief while diminishing the PWD's distress would be instrumental in supporting adjustment for them both.

The term transition implies a beginning and an end (Brooke, 1988; Schumacher & Meleis, 1994; S. A. Wilson, 1997) as does research that uses a transition period (Bauer & Nay, 2003; Boise & White, 2004; Garity, 2006;

Gaugler, 2005; Gaugler, Mittelman, Hepburn, & Newcomer, 2010; Kellett, 1999; Nolan & Dellasega, 1999; Ott, Sanders, & Kelber, 2007; Port, 2006; Schulz, 2004; Woods & Warren, 2007; Yamamoto-Mitani, Aneshensel, & Levy-Storms, 2002) or even the lay literature when it informs FCGs not to visit during the first two weeks to allow the PWD time to settle-in (Crouch, 2013). Because of the dynamic nature of dementia and dyadic interaction neither the PWD nor the FCG may ever complete transition. It would be important for FCGs, PWDs, and ALs to understand this. For example, if ALs ask FCGs to wait to visit until the PWD “settles-in”, what does this mean for the dyad where the PWD does not settle? How does the expectation that in 2 weeks to a month the period of upheaval will be complete impact the FCG and the PWD when it is not? When one thinks about the impact of a transition without end on distress for all parties involved, the importance of educating administrators and staff of ALs as well as orienting FCGs and PWDs becomes evident.

Research implications. Currently, research that examines the transition to AL using a time oriented approach potentially misses valuable information that would help facilitate care for the dyad living with neurocognitive decline. This would have been the case for this researcher if a lack of participants had not necessitated the modification of the recruitment plan. In this study 86% of the dyads never settled. Questions that remain unanswered when time limits guide recruitment include: What is the impact on the FCG who is unprepared for the possibility that the transition will remain incomplete? If clinicians are recommending the move to AL because the FCG is exhausted and continued

care is perceived as a detriment to their health, what happens when the PWD does not transition and the FCG feels compelled to be ever vigilant? What is the impact for the AL and the FCG when the AL recommends not visiting until the PWD settles-in and an untoward event occurs? If transition is not achieved by FCGs and PWDs, does the focus of this area of research need to be re-framed? By limiting investigation to those who are only 6-12 months out from the move researchers may be missing important information that will expand our understanding of a phenomenon that continues to impact the lives of an increasing number of people.

Safety: The driving force behind the move. Previous studies have identified characteristics of FCGs and PWDs such as wandering, sundowner syndrome, incontinence, caregiver burden, and living alone as predictors of the decision to move a PWD (Banerjee et al, 2003; Buhr, Kuchibhatla, & Clipp, 2006; Gaugler et al., 2000; Gaugler, Leach, Clay, & Newcomer, 2004). Although there were some characteristic similarities (wandering, sleep-wake cycles, living alone, caregiver exhaustion) to previous studies, this study enhances our understanding by identifying the FCGs' concern for the safety of the PWDs or the people around them as the driving force behind the decision to move the PWD. For these FCGs it was fear that the PWD would harm themselves or others that precipitated the move.

Theoretical implications. If one considers the dyadic interaction described above in conjunction with this finding and its impact on transition, one might consider Maslow's Hierarchy of Needs (1954) as a guiding framework.

However, this framework only examines the individual's need. It works well if you are considering either the FCG or the PWD, but as discussed above this is an interactive process where the situation needed to fulfill the individual need for safety may be different. For example, the FCGs in this study identified safety as preventing physical harm to either the PWD or those around them. For the PWD, safety may be perceived as feeling safe because their home was a familiar place where they had lived for many years and a source of comfort in a world that was becoming confusing. Safety for the PWD may also have been found in knowing the neighborhood or being close to their social network. Relocating to an AL may disrupt everything that makes the PWD feel safe leading to distress for both the PWD and the FCG. How one reconciles the needs of the PWD with the needs of the FCG is currently unknown. Examining reconciliation of needs using a dyadic interactive approach may be fruitful in our endeavor to understand how to facilitate a less stressful process for both parties.

Clinical implications. The PWDs definition of safety and the FCGs definition of safety need to be considered. Assessing each party's perspective and then developing interventions to meet the needs of both would seem a logical approach. For example, for the PWD who wants to remain in their home one might consider choosing an AL that is structurally similar to the PWD's home in an area that still supports interaction with their existing social network. This may facilitate the PWD feeling safer in the AL while meeting the FCG's need to keep them physically safe. Applying Jonsen, Siegler, and Winslade (2002) 4

topics method may prove to be valuable approach in reaching an equitable solution.

Research implications. Studies that focus on the individual FCG or PWD may gain an understanding of the needs of the individual; however, this approach may miss the juxtaposition of two different perspectives that require equal consideration to facilitate a mutual reduction in distress. By conducting studies that use the dyad as the unit of analysis it may be possible to develop interventions that would be effective for both parties. This may further expand our understanding of this complex process.

Maintaining connection. Multiple studies have demonstrated that caregiving continues after relocating to long-term care environments (Gaugler, 2005). What became evident in this study was each act of caregiving was performed as a way of staying connected, of not forgetting the PWD as the disease progressed. Even the smallest task, for example, filling a medication box on a weekly basis and taking it to the AL was used as a way to maintain that connection.

Theoretical implications. Potentially positive effects of family involvement for the PWD have been studied extensively in long-term care (Gaugler, 2005). What has not been studied is the concept of performing tasks as a way to stay connected. Does the desire for connection contribute to visitation patterns? Would attachment theory (Bowlby, 1969) applied to this caregiving relationship yield answers as to why some caregivers desire to remain connected while others do not and who might best be served by implementing

acts of caregiving after entering the AL? Because the participants in this study all identified their relationships along the continuum from close to extremely close it is unclear whether the desire to remain connected holds true in relationships on the opposite end of the continuum. Answers to these questions may expand our understanding of the dynamic process of caregiving after admission to AL.

Clinical implications. Knowing that tasks, even small ones, may help FCGs stay connected it may be possible to develop a list of tasks FCGs could do that would help provide that sense of connection. It might be helpful to make “transition packages” to be given to the FCG that would contain objects such as a pill box or a booklet that provides information about how to accomplish tasks such as obtaining incontinence supplies, supplemental feeding options, transportation alternatives, etc. specific to their location.

Research implications. Using the idea that performance of tasks has the ability to help FCGs remain connected to PWDs, intervention studies may focus on different acts that facilitate connection as the dementia progresses. These studies could also examine to what extent the connection supports the transition process.

Visitation. Prior studies indicated that visitation continues after the PWD transitions to an AL (Bitzan & Kruzich, 1990; Duncan & Morgan, 1994; Gaugler, 2005; Gaugler & Kane, 2007; Gottesman, 1974; Hopp, 1999; Kane et al., 1989; Port et al, 2001; Zarit & Whitlatch, 1992). Proximity to the AL, kin relationships, and relationship quality were previous found to affect the frequency of visitation (Gaugler & Kane, 2007; Kelley et al., 1999; Port et al., 2001; Ross, Rosenthal, &

Dawson, 1997; Yamamota-Mitani et al., 2002). This study extended our understanding by identifying fear as a strong motivator for visitation. FCGs in this study demonstrated that as fears subsided, the frequency of visitation also subsided. If the FCG was fearful, the frequency of visitation increased.

Despite written guidelines to the contrary, FCGs were allowed to come and go as they pleased. FCGs perceived this approach as helpful, if not physically taxing. One might conclude that the deviation from the written visitation policy was for the benefit of the FCG and the PWD and the need to ensure the PWD was safe and secure, but the possibility exists that the presence of family reduced the need for additional AL staff to be present to assist with the new resident.

In this study, ALs frequently contacted the FCG when the PWD became agitated to assist with calming the PWD. It is unknown if this was motivated by concern for the PWD or to reduce staffing needs. Some might argue that the ALs were shirking their responsibility by depending on or taking advantage of the fears being experienced by the FCGs. Whereas, others might consider this to be a way to reduce the emotional toll for FCGs who needed to know the PWD was being well cared for before they could relax their visitation schedule. Regardless of the reason the FCGs in this study found the openness of the visitation schedule comforting. However, without guidance from the AL staff, FCGs may inadvertently prolong the time for transitioning for the PWD.

Theoretical implications. A theoretical framework to explain the role of the AL staff, the FCG, and the PWD in visitation practices and the motivations

underlying the visitation patterns from each of the three perspectives could not be located in the existing literature. Expansion of our understanding of this process may provide knowledge that could be utilized to develop and test interventions to best support FCGs, PWDs and AL staff.

Clinical implications. The effect of fear on the frequency of visitation and the ability of FCGs to find balance suggests that nursing and AL staff may play an integral role in providing guidance and assurances that the PWD will receive the care and support they need. Those who lacked trust in the formal caregivers; had fears that the formal caregivers would not be able to handle the agitated behaviors of the PWD; or feared decline and death of the PWD had difficulty finding balance between visiting, self-care and learning to allow the PWD their own time. In the absence of guidance from the AL staff or assurances that they would provide the care and support needed for the PWD, some FCGs felt tremendous pressure to continue to provide intensive hands-on-care to their own detriment. By attending to the needs of the PWD and the FCG, nursing has the opportunity to help FCGs find balance and facilitate the comfort level of the PWD.

Research implications. This study suggests that visitation patterns are multi-faceted and necessitate examination from the perspective of all parties involved. Not enough is known about this phenomenon suggesting additional qualitative investigation is needed. Additionally, before quantitative studies can be performed that evaluate the impact of fear on visitation the development of a valid and reliable measure needs to occur. Further the recruitment challenges experienced during this study suggest the need to expand recruitment beyond

traditional approaches in order to recruit FCGs who have moved a PWD into AL. This is explored in more detail in the section on strengths and limitations.

Study limitations and strengths

Study limitations. In no way is this discussion intended to minimize what was learned from those who participated in this study; however it is important to acknowledge the limitations to this study that impact the credibility and transferability incurred due to the small sample size and homogeneity of visitation practices experienced by these FCGs. Credibility examines whether the findings are accurate representations of multiple constructions (Lincoln & Guba, 1985). Luborsky and Rubenstein (1995) suggest 12-26 descriptions in each sample group are needed to achieve an accurate representation. This goal was almost achieved with the 11 moves occurring in the neither encouraged nor discouraged group. The redundancy found in the description of transition experience of this group leads this researcher to conclude this is an accurate representation. However, both the encouraged and discouraged from visitation groups fell quite short of this goal. Consequently, the findings may inform future studies, but are not adequate to provide any credible conclusions for these two groups in this study.

The thick descriptions provided by the “neither encouraged nor discouraged” group in conjunction with the existing knowledge of transition experiences for FCGs supports transferability of these findings. But, the underrepresentation of the other two groups precluded the development of thick

description for the encouraged or discouraged resulting in the inability to transfer what we learned to other FCGs who find themselves in this situation.

The initial recruitment plan might have created the potential for bias because the AL administrators were the gatekeepers. However this was mitigated by advertising in printed material, posting a flyer at the Alzheimer's Resource Center, reaching out to nursing staff, friends of other FCGs, and utilizing the researcher's network of contacts in Alaska, Washington, Oregon, and Colorado. Self-selection also contributes to bias in that it only presents the description from the individuals who are motivated to contact the researcher. But, what about the voices we do not hear? The description that was not provided in this study: the caregivers who were encouraged to, or discouraged from, visiting during the transition; the perspectives of husbands, siblings, and sons with fathers who had dementia. It is not known why they did not participate; if there were actually FCGs who perceived they were discouraged or encouraged; if husbands and sons with fathers did not move the PWD to AL; or if the recruitment strategy did not reach these caregivers.

Study strengths. Despite the study limitations, there were strengths. Although the visitation practices in this sample were fairly homogenous, there was also sample variation. The sample included a wife and husband, daughters and mothers, a son and mother, and daughters and fathers. It included FCGs who had moved the PWD into both large and small AL facilities. It included FCGs whose PWD had died and those who were living. The age of FCGs ranged from 42 to 77 and the age of PWDs ranged from 71-94. Although no FCGs describe

the relationship with the PWD as not close, the descriptions of relationship quality ranged from “somewhere in between” to extremely close. The payment sources ranged from self-pay to Medicaid Choice waiver to Medicaid General Relief. The PWDs’ stage of dementia at the time of the move ranged from stage one to stage seven.

By expanding the time since the move from six months to no limitation it changed the way the transition was described and debunked the assumption of the researcher that “transition” encompassed a short time frame as was previously described by Wilson (1997) and Brooke (1988). Unlike moving to another home where one unpacks and begins the process of settling in to their new surroundings, these FCGs did not stabilize. The move and the time surrounding the move was an event, not a completed transition. The researcher would never have heard this important aspect of the description had the transition period been retained at six months.

Additions to the Body of Knowledge

This study offers the first description, to the researcher’s knowledge, of the interactive nature of transition for the FCG and the PWD when moving to assisted living. It further expands what is known of the fears that FCGs bring to the transition by introducing fear of rapid decline and death and fear of yet another move if the AL staff feels ill equipped to handle the agitated behaviors of the PWD. For the FCG who is discouraged it gives a glimpse at the potential of additional loss experienced by the FCG. It raises questions about the motivation on the part of the AL for relaxing visitation practices and the effect on the FCG of

relying on families to calm the PWD. This study further describes the concept of trust of the formal caregiver and fear as determinants of frequency of visitation.

Recommendations for Future Research

There is a litany of future research that needs to be accomplished based on the findings of this study. First and foremost I would recommend replicating this study using social media and on-line resources as a recruitment strategy to gain access to the FCG. The traditional recruitment strategies resulted in very little yield. Establishing champions not affiliated with the AL homes may also open the door to FCGs not accessed in traditional ways. As this study did not fully explore the transition for FCGs who were either encouraged or discouraged or the neither encouraged nor discouraged category, additional investigation needs to occur. Inclusion of husbands, sons and fathers, and siblings would also be beneficial when developing a theory of transition consistent with their description.

In order to capture the family centered approach, the PWD also needs to be included in the description. What is the effect of visitation and what are the circumstances surrounding the effects and how does desire for visitation impact the outcome? Several participants in this study expressed desire for increased social interaction for the PWD as one of their hopes for transitioning to AL. Is this important for the PWD? Are activities in assisted living protective for the PWD and FCG, do they help ease the transition? How does fear of the effect of dementia impact participation with others who have dementia? What agitates the PWD? Is it temporal or are there other factors? When does visitation yield a positive outcome for PWD, FCG, and AL staff? Under what circumstances is it

detrimental? These questions represent just a few of the answers left unanswered by this study.

SUMMARY

This study examined the family caregivers' experience of transitioning a PWD to assisted living and the impact of different visitation practices on the experience. The lack of completed transitions is one of the most compelling results of this study. Theoretical models need to be expanded to include the effect of dyadic involvement on transition. Additionally, the impetus for the move for these FCGs was based on crises with the driving force being safety for the PWD and those around them. This driving force was coupled with FCG exhaustion for FCGs who were providing care in their own homes. Whether the decision itself was easy or hard there was still significant emotional turmoil surrounding the move with FCGs using multiple strategies to maintain connection between themselves and the PWD.

FCGs described fear as a major motivator for visitation. Fear that the PWD would not be well cared for; fear of harm to the PWD; fear of decline and death; and fear of yet another move contributed to frequent visitation. This study also highlighted the desire to remain connected contributed significantly to choices in visitation patterns when the FCG was neither encouraged nor discouraged. For the FCG who was discouraged from taking her mother to church in the evening because of increased agitation, this study illustrated the loss that was felt in addition to the losses already being experienced through the dementia process. The importance of understanding the transition, the dyadic

interaction, and the impact of visitation practices supported by AL are apparent in the results of this study.

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Appendix A

Interview Guide

Introduction: Thank you so much for agreeing to meet with me today. I sent you a copy of the informed consent to read through after we spoke. I'd like to take a few minutes to go over it to be sure everything is clear and answer any questions you might have before we begin, I'd also like to remind you if you have concerns and do not wish to proceed after we go over the consent that is perfectly alright too. You just need to let me know one way or the other by signing in the appropriate spot here at the end of the consent. [Provide overview of consent, i.e., the purpose, risks, benefits and alternatives] **Recorder on**

1. I'd like to start with just getting to know (PWD) a little bit. What was h/she like before being diagnosed with dementia? How would you describe him/her today?
2. Would you describe what your relationship has been like over the years...so both before and after diagnosis?
 - a. Probe: How would you describe the closeness of your relationship? Would you help me understand what that looks like?
3. How do you feel that affects things now?
4. So, let's talk a little bit about the actual move? How would you describe the circumstances that lead to the decision to move (PWD)?
 - a. Probe: Was it anticipated or a surprise?
 - b. Probe: How much time did you have to make the decision?
5. What was that like for you?
6. How did you choose this particular home?
 - a. Probes: (reputation, cost, proximity, staff availability, single/double room, etc)
 - b. Probe: Who helped?
7. Before you moved him/her what did you expect the transition was going to be like?
8. How long did you think it will take to adjust?
9. What were your greatest hopes for the move?
10. What were your greatest fears?
11. How has this played out?
12. What the day was like when you physically moved him/her to the home?
 - a. Probes: For you? For PWD?
13. Would you tell me a little about what the first few weeks (and months) were like? And now?
 - a. Probe: Were there challenging parts?
 - b. Probe: Were there circumstances that made it easier?
14. What could have been improved?
 - a. Probe: When you think back on the move, what might you have done differently?

15. How would you describe the visitation policies of the home when you first moved in?
16. Some people share that they are encouraged or discouraged from visiting while their relative is settling in and some say that neither happened. How did this happen for you?
 - a. Probe: Were you encouraged, discouraged or neither from visiting in the beginning?
 - b. Probe: Did someone provide direction?
 - c. Probe: Did you feel you could override the recommendation/direction?
17. How often do you visit or call? Would you describe how you arrived at this schedule?
18. Looking at your experience of transitioning PWD from home to here, what would you want to tell another family caregiver who may be considering a similar move?
19. Is there anything else you would like to add or are there other questions you were waiting for me to ask?

Closure: Thank you for your time. Is it ok to contact you, if I need clarification? I want to be sure that I accurately describe what I've heard from people so after I've interviewed everyone and have put together an understanding of what all of you have told me, would you willing to review my write up to see if it rings true for you?

Appendix B

Demographic Information

DC # _____

PWD

1. Age	
2. Gender (male/female)	
3. Last grade completed	
4. Caregiver identified stage of dementia from Global Deterioration Scale	

FCG

1. Age	
2. Gender (male/female)	
3. Kin relationship to PWD	
4. Length of time caregiving prior to transition	
5. Last grade completed	
6. Distance from your home to the assisted living home	
7. Describe relationship with PWD as	
a. Close	
b. Not close	

DC # _____

AL

1. Visitation policy (House Rules)	
2. Total number of beds	
3. How many people live in the home?	
4. Are there other residents with dementia in the home? Yes/No/Unknown	
5. If yes, how many?	
6. Are there other residents without dementia in the home? Yes/No/Unknown	
7. If yes, how many?	
8. Who pays for your relative to live in the assisted living home? Self, Medicaid, Long-term care insurance	

Appendix C
GLOBAL DETERIORATION SCALE
DC #_____

Some health-care professionals use the Global Deterioration Scale, also called the Reisberg Scale, to measure the progression of Alzheimer's disease. This scale divides Alzheimer's disease into seven stages of ability.

Stage 1: No cognitive decline

- Experiences no problems in daily living

Stage 2: Very mild cognitive decline

- Forgets names and locations of objects
- May have trouble finding words

Stage 3: Mild cognitive decline

- Has difficulty traveling to new locations
- Has difficulty handling problems at work

Stage 4: Moderate cognitive decline

- Has difficulty with complex tasks (finances, shopping, planning dinner for guests, taking medication)

Stage 5: Moderately severe cognitive decline

- Needs help to choose clothing
- Needs prompting to bathe

Stage 6: Severe cognitive decline

- Loss of awareness of recent events and experiences
- Requires assistance bathing; may have a fear of bathing
- Has decreased ability to use the toilet or is incontinent

Stage 7: Very severe cognitive decline

- Vocabulary becomes limited, eventually declining to single words
- Loses ability to walk and sit
- Requires help with eating

Reisberg, B., Ferris, S. H., De Leon M. J., & Crook, T. (1982). Modified from Global Deterioration Scale, *American Journal of Psychiatry*, 139, 1136-1139.

Appendix D

Informed Consent

IRB#: 00010368

Research Consent Summary

You are being asked to join a research study. You do not have to join the study. Even if you decide to join now, you can change your mind later.

1. The purpose of this study is to learn more about your experience with placing your family member in an assisted living home.
2. We want to learn
 - a. About the family caregiver's experience of moving a person with memory changes (dementia) from home or another assisted living environment and
 - b. How different visitation recommendations (encouraged to visit, discouraged from visiting, or neither encouraged or discouraged) affect that experience.
3. Everyone who joins the study will fill out a survey. You will also be interviewed about your experiences in placing your family member in assisted living.
4. If you join the study, you will be asked to complete an interview where the investigator will ask you about what it has been like for you to move the person with memory changes and how you feel the visitation recommendations influenced what it was like for you. The interview will last approximately 60-90 minutes. The interview will be recorded and then typed. The researcher may contact you to clarify your answers. If you agree, you may also be asked to look at the final description, after everyone who wishes to participate has been interviewed, to see if the researcher's description rings true for you.
5. There is a small risk of breach of confidentiality.
6. If you agree, information collected during the study may be saved for future research.

IRB#: _____

Research Consent and Authorization Form

TITLE: Assisted living homes and the dementia caregiver: Do visitation recommendations matter?

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

CO-INVESTIGATORS: Kathryn Sexson, MS, FNP (907) 242-8978

PURPOSE:

You have been invited to be in this research study because you have been a family caregiver who was very involved in the care of your relative with memory changes prior to moving to assisted living. The purpose of this study is to learn more about the move to assisted living and how the family caregivers' understanding of the assisted living homes' recommendations about whether you should visit the person with memory changes (dementia) or not during the settling-in period affects the experience of moving for the family caregiver.

You will be interviewed once. The interview will take approximately 60-90 minutes to complete.

Up to 40 participants will take part in this study.

PROCEDURES:

You will be asked to complete an interview where the study nurse will ask you about what it has been like for you to move the person with memory changes and how you feel the visitation recommendations influenced what it was like for you. The interview will last approximately 60-90 minutes. The interview will be recorded and then typed. The study nurse may contact you to clarify your answers. If you agree, after everyone who wishes to participate has been interviewed, you may also be asked to look at the final description, to see if the researcher's description rings true for you.

You will be asked to provide some information about yourself, your relative, and the assisted living home. This information includes the age, gender (male/female), highest grade completed, stage of dementia (memory loss) for the person with dementia and your age, gender, relationship to the person with

dementia (wife/husband/daughter/son), how long you were caring for them before the move, highest grade completed, how far the assisted living home is from your home, whether you would describe your relationship as close or not, how the monthly rent is paid (you pay, Medicaid pays, or you have insurance that pays). In addition, you will also be asked about the assisted living home whether it is a for-profit or not-for-profit organization (if you know) and whether there are other people in the home who have memory changes.

You will be asked to complete the Global Deterioration Scale. This scale will help us understand where your relative is in the progression of his/her memory loss. This should take approximately 5-10 minutes to complete.

During this study each interview will be audio-recorded. The recording session will last as long as the interview (60-90 minutes). The recordings will be typed and the typed transcripts will be used for the study. The audio-recordings will be destroyed when the study is done.

If you have any questions regarding this study now or in the future, contact **Theresa Harvath** (503) 494-3855 or **Kathryn Sexson** at (907) 242-8978.

RISKS AND DISCOMFORTS:

During the course of the interview some of these questions may seem very personal or embarrassing. They may upset you. You may refuse to answer any of the questions that you do not wish to answer. If the questions make you very upset, we will help you to find a counselor.

BENEFITS:

You may or may not personally benefit from being in this study. However, by serving as a participant, you may help us learn how to benefit family caregivers in the future.

ALTERNATIVES:

You may choose not to be in this study.

CONFIDENTIALITY:

We will take steps to keep your personal information confidential, but we cannot guarantee total privacy. The investigators, study staff, and others at OHSU may use the information we collect and create about you in order to conduct and oversee this research study.

We will not release information about you to others not listed above, unless required or permitted by law. We will not use your name or your identity for publication or publicity purposes, unless we have your special permission.

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

Data from this study may be shared with other investigators for future research studies. All identifying information about you will be removed from the samples before they are released to any other investigators.

We may continue to use and disclose your information as described above indefinitely.

COMMERCIAL DEVELOPMENT:

Samples and information obtained from you in this research may be used for commercial purposes, such as making a discovery that could be patented or licensed to a company. There are no plans to pay you if this happens. You will not have any property rights or ownership or financial interest in or arising from products or data that may result from your participation in this study. Further, you will have no responsibility or liability for any use that may be made of your information.

COSTS:

There will be no cost to you or your insurance company to participate in this study.

You will receive \$10 for each interview in appreciation of your participation.

LIABILITY:

If you believe you have been injured or harmed while participating in this research and require immediate treatment, contact **Kathryn Sexson: 907-242-8978**.

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.

PARTICIPATION:

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. You do not have to allow the use and disclosure of your health information in the study, but if you do not, you cannot be in the study.

If you do join the study and later change your mind, you have the right to quit at any time. If you choose not to join any or all parts of this study, or if you withdraw early from any or all parts of the study, there will be no penalty or loss of benefits to which you are otherwise entitled, including being able to receive health care services or insurance coverage for services. Talk to the investigator if you want to withdraw from the study.

The information that we will collect from you will not be stored with your name or any other identifier. Therefore, there will not be a way for us to identify and destroy your materials if you decide in the future that you do not wish to participate in this research.

We will give you any new information during the course of this research study that might change the way you feel about being in the study.

Your health care provider may be one of the investigators of this research study and, as an investigator, is interested in both your clinical welfare and in the conduct of this study. Before entering this study or at any time during the research, you may ask for a second opinion about your care from another doctor who is in no way involved in this project. You do not have to be in any research study offered by your provider.

SIGNATURES:

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

We will give you a copy of this signed form.

Subject Printed Name	Subject Signature	Date
Person Obtaining Consent Printed Name	Person Obtaining Consent Signature	Date

Appendix E
Descriptive Analysis Memos

Descriptive Analysis Memo - DC #1
Pseudonym: Jacque and Tom

Kin relationship: Daughter and Father

Age: FCG 61, PWD 87

Stage of dementia: 5

Education:

FCG: Completed high school and 1 year college

PWD: Completed 10th grade

FCG health: Good

PWD status: Deceased

Length of time caregiving before move: 1 year

Quality of relationship: Close

Time since initial move: 2 years

Durable power of attorney: FCG

AL: Small home, 5 beds, all with dementia in all 4 facilities, 4 moves spanning 2 years, most recent 5 months ago

Distance to facility: 3 miles

Visitation policy: Open

Payment source: General relief and self-pay

Before dementia: Angry man, forever frustrated, hated clothes, loved to flirt/hated men, hard worker, neat and tidy. "I won't say he wasn't loving, but he wasn't a very caring, outgoing, nurturing personality." (494-495)

Relationship

"We were close", "I was daddy's little girl", "Found out he cheated on my mother and then we had issues with that...at the end we got close" (479-484)

"My brother actually got closer to him at the end" (491-492)

"We did get close and we got to share a lot of things" (498-499)

The impetus

The first move from his home to hers: Fall and memory issues (13-15).

I was spent. I'm tough, strong person, dealt with a lot. I could NOT do that. I just couldn't. I don't have the patience. I just don't have the patience for it. And like I said, the fact that he's out roaming around on the yard in the snow. It's like having a newborn and not being able to stay home with him. (818-837)

Safety: Wandering outside in the snow (820-821). I couldn't keep him safe. You can't lock him in, You can't. but I wanted something that there was-there needs to be something so that he couldn't get out or I would've heard him, something he couldn't have figured out right away so I didn't know where he was because at midnight, catching out of the shower scared the hell out of me. What would've happened if he'd fallen through the glass?" (820-830)

Exhausted: We weren't getting any sleep. They heard a noise and they were up. (832-835)

The second move: Get him away from conflict

The third move: Get him to a place with more interaction

The final move: Evicted from 3rd home

The initial move decision

Day program so they could work

We were awake continually and listening for 5 months (70-78)

In October, Jie spent the last week in the hospital in critical care (99-100)

After denied the choice waiver in October (while Jacque was in the hospital) (102-112), Tom had a heart attack or stroke and ended up in the hospital (114-115)

We can't do this, he's got to go to assisted living (116-118)

The initial move

Hospital helped obtain general relief funding and find home (118)

Very rushed – only had 3 days before they had to kick him out of the hospital (120-122)

Hardest thing: He didn't wanna go and didn't want me to leave him there and literally called me continually. All the time. "You gotta get me out."

"You gotta get me outta here. You gotta get me outta here. You gotta come get me." I'd pick him up, have him for a few hours, drop him off and then he'd be calling on the phone, "You gotta come get me. I can't stand it here." So, it was very difficult, especially at the beginning. (743-752)

Shared a bathroom with another man (dad cannot stand men), "let me tell you that didn't work (123-125)

Dad still very angry, banging his cane on the floor, yelling at people (126-127)

Escaped (934-942)

The second move

ALF requested secondary to disruptive behavior (128-129)

Moved into a modified duplex with wall removed, so each side was a mirror image (128-134)

He would call and say "there's no food in my house. I need you to bring me some groceries so I can have something to eat. And I'd say Dad they feed you there and he'd say, "that's news to me, I didn't know that." (136-140)

"He was so disconnected because of the setup" (144)

Worker's spoke foreign language and watched foreign language television: "No one sat in the living room to watch tv together, they had no activities, they had nothing, and the minute he got on general relief his Day Care stopped, they never took him anywhere, nothing. They couldn't understand him and he couldn't understand them." (151-162)

The third move

I was so unhappy with 2nd house (187)

Subjected myself to the whole process (187-189)

Thrilled with third place (189-190)

The eviction

Begged them to let him stay: “You’re going to take a year off his life if I have to move him again” (223-225)

Had to move him: Dead 4 months later (225)

No recourse: If they give you 30 days, you have to be out in 30 days. It’s their house, they have every right to kick them out (312-316)

The fourth move

One on one with caregiver for a month (new home, no other residents) (401-402)

Heavy sigh (455)

Didn’t take many of his things (455-456)

No family pictures, he didn’t recognize them (472-473)

“Couldn’t have asked for a better – I wished he’d gotten to spend more time there...” (557-558)

The first two weeks is hell (219)

Calls continually, he was so upset he wanted to go and wanted to go back to his other place because he didn’t know any better (219-223)

“It was hard” (612): All the moves were tough. It was harder when he had his cell phone. He was calling me continually and eventually we had to get rid of the cell phone (because he was taking it apart and burning it) (612-614)

“It was tough” (633): All of that whole learning process of all – was tough – all of that’s tough. It definitely is tough on the caregiver (633-635)

Caregiving continues

“I took him to all his appointments. I managed all his medications. I’d bring a med pack and stuff because there was no way I could afford the medset pharmacy stuff.” (163-171)

Quit taking her medication to pay for his (off tape)

Visitation: Open – “it never came up at any of them. I came and went whenever I felt like I needed to or could or had the time or whatever” (711-712)

The cell phone: “He would call from the home he’d be like “You’ve gotta come get me, you’ve gotta get me out of this place, come get me, come get me.” There’d be times she’d get back home and the phone would ring and it was him calling, “you’ve gotta come get me out of this place, I need to get out of here”. (176-181)

Brought him home to visit a lot when he was in the first 2 homes
(182-187)

“The only time he’s happy is when you come to visit him or you pick him up” (475-477)

“I’m going over after work. I’m going on Sundays, spend a couple of hours. I literally didn’t have four or five days in a row where I didn’t go see him. I think it was kind of like a bit of relief to actually know I could be sick and not go.” (643-647)

Choosing the home

Financial status: “You can whistle Dixie to find an assisted living house for people on general relief” (266-267)

Openings (263, 284)

Some homes are gender specific

Turned down over and over: nope, nope, nope (264)

Proximity is a luxury (299-304)

“It’s almost impossible to find anywhere that is regular people that understand English and can read and speak and like I said, people that are not having to be there 24 hours a day to take care of these people. I mean I don’t know when they sleep.” (396-399)

He never settled (402-404)

“He never sleeps. He’ll sleep for 15 minutes and then he’s up walking around” (403-404)

Greatest hope: That the conflict would go away (783) (move 1-2). Move 2-3 To get him somewhere where he had more interaction and they would hopefully do more with him (795-796)

Greatest fear: Not enough medical, needed more than somebody to babysit him and feed him three meals a day (812-815)

The disease:

Frustrating (521)

Finding the humor (508-519)

Men didn’t bother him any more (528-529)

The pictures

Navy uniform (16 years old – 1944) served his country

Descriptive Analysis Memo - DC #2
Pseudonym: Nancy and John

Kin relationship: Wife-Husband

Age: First move: FCG 77, PWD 81
 Second move: FCG 79, PWD 84

Stage of dementia:
 First move: 1-2
 Second move: 6-7

Education:
 FCG: Completed Diploma program in Nursing
 PWD: Completed BA in Teaching, 1 class post

FCG health: "Pretty good"

PWD status: Died 6 weeks after second move

Length of time caregiving before move: 2 years "from the time moved into AL"

Quality of relationship: Close

Time since move:
 First move: 2 years
 Second move: 8 weeks

Durable power of attorney:
AL: Small home, 5 people, all with dementia

Distance to facility:
 First move: Shared same apartment
 Second move: 2 miles

Visitation policy: Open
Payment source: Medicaid choice waiver

Relationship: She describes their **relationship** as trusting, loving and seldom disagreed (147). This continued throughout their marriage and through the cognitive changes. He used to look for her in the ALF by stopping people and asking, "Have you seen my sweetheart?"

First move was from home to an aging in place ALF of <50 residents. This move occurred early in the disease process between stages 1 and 2 of cognitive impairment. The couple moved together into an apartment and the decision to move from home was a mutual decision. This move was precipitated by the diagnosis of Parkinson's disease and the start of mild cognitive change coupled with the reality of knowing things were going to progress. This move was uneventful, just one in a series of moves over their lifetime. Their philosophy had always been, "Honey, home is wherever you are" (151). They had applied for and received the Medicaid waiver prior to the move and consequently were funded for all but \$1300 of the \$5000 monthly rent.

The second move (begins line 381): Significantly different than the first. “Decision to move made for me”. Crises precipitated the move. The **false start** occurred after he entered someone’s apartment next door to the place where he had tea and cookies. “They said we had to leave” (this was October). Daughter said, “no we can’t move him, he’ll go downhill too fast” Had a reprieve until June when “he was just out of his head” and dismantled their apartment. She and an aide locked themselves in the bathroom and called 911. By the time the police arrived he was standing outside in his shorts. She knew this would be the thing that made him move. She wanted to be the person to decide so “told them we were gonna look for another place”.

Found a place that came highly recommended so didn’t feel the need to investigate, but, still very distressful. Chose not to tell him in advance about the move because he would perseverate. Still questioning that decision. He asked her if they were separated. Before the move he slept through the night. After the move, it was hard for him to sleep at night, he was agitated. The home would call because he was up. Memory became worse. Hospitalized 3x in 6 weeks.

Greatest hope: “I don’t know if I’d lost hope by then”. “I guess that he would be comfortable, he would sleep, he would eat.”

Greatest fear: “That they might not be able to keep him”. “It wasn’t spoken or anything” but thought about it.

Open visitation: She stayed with him around the clock the first few nights and slept in the chair until her daughter intervened. Then the daughter stayed with him episodically. Went every day. First week was there for morning and evening meals. Then our daughter did his diabetes care in the morning (ALF personnel cannot administer insulin unless a LPN/RN) and I went at noon and stayed until supper time and the administrator (RN) would give night time insulin.

Policy allowed the family to try to help the PWD adjust to his new environment. It may also have helped the AL because he was distressed and would have otherwise required increased attention from staff. This might have threatened the security of the placement. The family had already experienced that John’s behavior could lead to forced relocation.

Additional Stressors:

Multiple family crises: Son sarcoid exacerbation

Being robbed during the first move, moved by people from her church

Descriptive Analysis Memo - DC #3
Pseudonym: Barbara and Jane

Kin relationship: Daughter (long distance)-Mother

Age: FCG 56, PWD 85

Stage of dementia: 6

Education:

FCG: Completed PhD program in Nursing

PWD: Completed AA in Business

FCG health: "Pretty good"

PWD status: Deceased

Length of time caregiving before move: Almost 1 year

Quality of relationship: Really close

Time since move: 4 months

Durable power of attorney: Brother

AL: Facility, 45 beds, Approximately 50% with dementia

Distance to facility: 12 hour flight

Visitation policy: Open

Payment source: Self-pay

Before dementia: Active and independent

Relationship: Describes as "really close" (188). They traveled together, talked frequently and visited each other

Effect on decision to move: "it was easy", staying home "wasn't safe for her anymore" (248-254). "I think that was really helpful, that my mom and I had a good relationship you know, and I wanted her to be comfortable. I didn't want her to suffer, but I wanted her to be in a safe spot, which meant not being left at that house in the country, you know, that when the pieces started coming together, the rest of them realized I wasn't being the mean daughter; I was being the loving daughter who wanted the best for her mom" (582-590)

Problem: Having remainder of family recognize need to relocate to safe environment. Originally suggested in December, kept pushing through January (254-263). By end of January really started talking to brother (DPOA) about looking at facilities (271-273), but he remained resistant ("really kinda put up a fence, a brick wall" (276-277)).

The transition:

Started falling more in January and having rapidly accelerating cognitive issues (254-263).

The crisis: Fall in February, resulted in hospital admit, transfer to rehab facility, then quit progressing, LD CG flew in and guided the decision to keep in AL

In through the back door: Provided LD Caregiver with ability to access the healthcare system to ultimately achieve AL move

“Ganging up on my brother” (323): Working with other family members to facilitate as DPOA resistant

Choosing the home: Small town, only 3 care facilities; some in next town over (15 miles away). LD Caregiver advised DPOA to get her on the wait list for all 3 then go to neighboring town. (331-351)
Initial move for rehabilitative services to 2nd choice in home town.

The journey to final decision of AL: DC #3 is convinced staying AL is best for her mom. So when flew in started by discussing the distribution her mother’s things away (mother not informed until after the decision was made).

The shock: “They were looking at me like, “Well, don’t you think she’s gonna be, like, going back there?”

I remember looking at my brother and his wife and their youngest son and saying, “No, she’s at the assisted living home. That’s where she needs to stay. It is not safe for her to return to that house.” “She’s not returning to that house, and we need to talk about it, because,” I said, “undoubtedly, you think she’s going to be returning. And I can tell you from a healthcare perspective, as a nurse,” I go, “She should not be living there anymore.” You know, and they all three just looked at me with this look of like, you know, because I was just like, “I’m not going to beat around the bush, you guys. I’m just putting it out there, you know?” And then I went on to say something new like, you know, “As her daughter,” I go, “I would love to have her living on her own”.

“She could do that last year. She can’t do that now.” I go – they go, “But you haven’t even seen her.” And I go, “No, but I’ve talked to her.” And I go, “I can visualize the change that has occurred. I go, “I was here last April, I was here last July. I came back in December. This is now March. The only thing that I have seen is a steady decline. And since September, it has been a rapid decline.” And they kind of were just like, “Oh, my gosh.” (413-429)

Sister-in-law said “We might want to keep – keep it (the dining set) there for a little while longer”. And I go, “We can keep it here for a little while longer, but we need to start changing the focus”. *This is what I call the swooper, have to be careful about my own feelings.*

16 yo niece helps to set the tone so DPOA was on the same page by the time they needed to make a decision with the home on Tuesday.

The DNR conversation (not sure needs to be part of this). *Just illustrates that the decision was about what LD CG wanted/needed to happen (even though may have been best for mother’s safety difficult for her brother (DPOA))*

The family relied on me: “He would write down exactly what you wanted him to do, or what you wanted him to check up on. She goes, “he total got into you helping with, you know, managing your mom’s care” (578-581).

It’s all about safety: “I wanted her to be in a safe spot” (586). “Mom, I know you really want to be at home. Your home is no longer safe for you...The issue is where is a safe area or a safe spot for you to live.” (613-624)

Breaking the news: “I really thought I’d be home by now”. “Mom, I know you really want to be at home. Your home is no longer safe for you...The issue is where is a safe area or a safe spot for you to live....She looked at me in that way she would and said, “Oh...so this is my home” and I go, “this is your home now”.

Listing the positives: You are two blocks away from where your daughter-in-law teaches school, eight blocks away from your son....you’ll have lots more visitors. You won’t have to worry about cooking anything or having someone make you something...we can take your room, because you have a single room, and we can decorate it with your stuff” (608-649)

Just the facts: “I would give her the truth”. “I wouldn’t say, “Oh, you’re just going to be here a few more weeks, it was like, “No, I’m going to tell you that you’re not going home” (819-824)

Mom’s transition:

Mom’s reaction: She wasn’t happy with me on that Wednesday, but by Saturday she was smiling

Visitation: Someone visited every day. And I think that was part of the saving grace for her. My brother stopped in every evening on his way home. My sister-in-law would pop over on her lunch break. My niece would pop in two-three mornings a week and bring the great granddaughter. My nephew would stop in with her great grandson once a week. I think those things really helped her feel like it wasn’t so bad. (777-794)

Maintaining contact for this CG was more challenging because they didn’t give her a phone (918-919) because she couldn’t remember numbers. Talked when brother was there via his cell. After hospice started, I really didn’t talk with her then because she was just cognitively not there. (946-947)

Choosing the home: No rooms in first choice so made decision based on bed availability and location

Greatest hope:

- Be Safe
- I wouldn't worry: "Having her at home was very stressful", "I fretted a lot", "always that kind of like uneasiness" (852-872)
- Met my goal (1230-1231) safe and comfortable in the end

Greatest fear: "I really didn't have any because I knew it was for the best for her" (905-906)

Hardest part:

Gone before they're gone: After hospice started, I really didn't talk with her then because she was just cognitively not there. (946-947)

For them it was like this rude awakening: She wasn't the same person that she had been for 84 years

See the signs, but can't accept: Took the car keys, so they were starting to see some of the judgment, but there were things that they just quite weren't ready to accept.

Am I alone? I'd like to know how my experience compared to other people's. It's not something that we talk about in society.

Descriptive Analysis Memo - DC #4
Pseudonym: Maryann and Jack

Kin relationship: Daughter and Father

Age: FCG 42, PWD 71

Stage of dementia: 5-7

Education:

FCG: Completed BA in business

PWD: Completed high school, vocational certificate and some college

FCG health: Good

PWD status: Living

Length of time caregiving before move: 10 months

Quality of relationship: Extremely close

Time since move: 9 months

Durable power of attorney: FCG

AL: Facility, 48 beds, 100% of 14 people on dementia unit, don't know about other part of the ALF

Distance to facility: 5 minutes

Visitation policy: Open

Payment source: LTC insurance and self-pay

Before dementia: Active and independent, had really strong friendships, very smiley, friendly, kind, very dry sense of humor, generous to a fault, loves to laugh, loves to make people laugh, not always able to emotionally express himself, very laid back, knew you were loved, a good provider, not a huge adventurer, very loyal, "he had a big heart" (368).

Relationship: Extremely close (190). "Definitely gotten better, gotten closer" (478-496). "Bond has grown stronger over the years" (497). "My heart just so softened...with his issues, always been a man's man" (499). "Now, he's obviously very vulnerable, needs a lot of assistance and I know that's been hard for him." (500-501) "He relies on me to help take care of him." (513-515)

Impetus: Not comfortable with my dad being able to care of himself (3-4), home 40 miles away (6), hired home healthcare agency (7-8), fell downstairs developed life threatening subdural hematoma in October (10-20), needed more eyes, the commute, variable quality of home health care workers (10-30). Wouldn't feel comfortable leaving him alone for even an hour (73-75). After the third fall, "I thought to myself, how many more red flags do you need?" (1210)

The defining event: The third fall down the stairs. "The fall changed everything" (1224)

The promise: His desire was to stay at his house as long as he possibly could safely. I promised him that (139-140)

First fall March: Brought to their home, hired contractor, made his home handicap accessible with safety features (railings, grab bars), moved back home

Second fall: Slipped at their home

Third time: The “big fall” in the hospital for ¾ of October.

Sold his house: 2 weeks prior to the interview

Advance planning: “It’s been a blessing”

“He did everything down to a healthcare directive; I mean no guesswork involved for me.” 324-325

Being a good steward of his finances (291-298)

Emotional roller coaster/The gambit of emotions

“Stress at lots of levels” (298)

He was just laughing. And I remember thinking **I miss that!** (394-395)

Doesn’t always jump up and down for joy when I walk into the room. He’s so used to me coming by, when the kids were home for the summer, he was so excited! He doesn’t do that when I come in (509-513) *does this go here????*

The third fall: “Nobody thought he was going to make it through”

“It wasn’t easy to move him out of his home” (597-602). It seemed like it made the most sense with all of the situation being what it was (598-99)

“When that day actually comes it’s just so many emotions that you’re not even sure you’re ready to deal with and what do you do with them now that they’re here? (620-623)

“It makes me sad” (637-638)

“Even some relief”: He was going to be five minutes away (640-641)

“I’m gonna be losing it too if we don’t figure out something” (753-754)

“So much hurt and emotional anxiety” (1156-1157)

“It (the disease) comes fascinating and ugly and horrific to walk the journey”

Who is he now?

Anxious and paranoid (373-374)

He was just laughing. And I remember thinking I miss that! (394-395)

The glimpses: “That’s my old dad” (410-411)

The move

“He was so anticipatory” (560). He didn’t sleep the night before (560-561). “Almost wish the caregiver had not even told him” (561-562)

Is he going to have appropriate care here? (563)

Is somebody going to take him under their wing, so I don’t have to worry about him so much, before I didn’t worry (564-568)

Lots of unknowns (569)**Monitoring the care and adjustment (581)**

Overwhelming: His gait was off, he wasn't walking well. He made me nervous. The furniture wasn't to scale. It just felt overwhelming. (604-612)

Second guessing: Was it selfish of me? Should I have looked at places a little more in depth by his home? Moving him out of his social network, what would that do? (620-634)

Guilt: Associated with him being there or moving out of his home or what (575-576)

"felt like if I could physically do some things maybe it would help me feel better and then also being there and seeing how he was adjusting" (579-581)

Initial Visitation motivated by guilt/fear: There every day before work, after work, taking home his laundry, doing his laundry

The broken promise: I wasn't regretting the decision, it was just the actual move had so many emotions tied to it because it was the day I promised my dad and myself that wouldn't happen actually. It was hard. () It was a difficult step for us, for me, to realize we just couldn't do it (1187-1188)

Making peace: He "agreed to doing whatever we needed to do to keep him safe. That gives me peace when he has hard days and good days and all of his days, we know that he was part of the process when he was able to be part of the process." (1045-1049)

The transition period

The familiar face: Hired the "extraordinary caregiver" for 8 hours Monday-Friday during the day for the first couple months

"He did quite well" (652) He was pretty fragile from the fall when we moved him in. "He's only really just kind of gotten healthier physically"

He wandered into other people's rooms quite often (659-660)

The Decision:

Talked about it: "Had conversations where he knew that was going to happen even before his fall when he had more clarity and he agreed to it"

When the day came: Gambit of emotions (640), second guessing (623), questioning

I can't move him back...."I can't keep worrying" (593)

"Looking for a better way...there just has to be a better way" (601)
Should I...

It makes me sad; it's just part of the consequences of making a decision, which was my fear early on (639-640)

Pro/cons list: Had the pro/con list going and we still were way more on the pro column. We went forward and tried to support that decision as best as we could at that point in time (643-646)

Financially: made sense (684-689)

The backup plan: Felt like we could go back to 24 hour in home if we had to, held on to his house for 9 months (688-690). We had other options (694)

Safety: The bottom line (756-784): The driving decision maker...is if safety's compromised or not

Choosing the home 788-972

Husband found it, not sure how

Initially wait listed greater than one year ago for regular room, once developed hallucinations/paranoia, after fall in October called and requested dementia unit, they had an opening

Only place they toured, other one they liked had wait list

Had his own space

Activities

The Lesson: We learned our limitations really quickly about we can't do this well. We need to be honest with ourselves and with dad. (1212-1216). "It was a difficult step for us, for me, to realize that we couldn't do it." (1186-1187)

It couldn't be our house (695-696): That really took a toll on us as well (696)

Hope is a funny thing: Throughout this process, it's just sometimes it's very elusive and very hard (986-987)

Greatest hope: To see him more. Be able to walk this journey of the end of his life to be a little bit more engaged (983-985)

Learning to enjoy the little things: Hope is going the night before last and listening to him laugh like a little kid at silly little videos on TV (1001-1002)

Being present for him (1004-1005)

Ending it all: Not so good. I was thinking about ending it all. I'm just not very happy.

Greatest fear: The worst case scenario...possible decline to the point where the residents don't even make it and die (1010-1012)

Descriptive Analysis Memo – DC #5
Pseudonym: Michael, Jenny, and Karen

Kin relationship: Son and daughter-in-law-Mother

Age: FCG (son) 53, FCG (daughter-in-law) 51, PWD 77

Stage of dementia: 4

Education:

FCG: Son: Completed BA; Daughter-in-law: Completed BS

PWD: Completed BA at 50 and all but thesis of Master's after age 50

FCG health: Son: "Excellent"; Daughter-in-law: "Good"

PWD status: Living

Length of time caregiving before move: Long distance for almost 2 years prior

Quality of relationship: Close - "Somewhere between close and not close"

Time since move: 4 years

Durable power of attorney: FCG

AL: Facility, 48 people, Approximately 85% with dementia

Distance to facility: 750 miles

Visitation policy: Open

Payment source: Self-pay

Before dementia: Active and independent

Relationship: Somewhere between close and not close. Difficult individual. Probably as close to her as anyone in the immediate family. Not real close, but always kept in touch (86-89)

Effect on decision to move: "Since I didn't feel like I really had a lot of choices, I guess I didn't choose to be too concerned about that." (575-576)

The impetus:

Initially, could no longer drive, couldn't pass the written driver's examination, healthcare evaluation resulted in recommendation for her not to live alone. (271-280)

Risk of harm to others: Leaving the stove on, plugging the sink and forgetting to turn the water off, putting things next to electric heat and having them melt (345-353)

Self-care poor: Diet poor, food rotting in refrigerator (356-361)

Safety: "For her own protection as well as the people she was living around" *Want to protect them, duty to protect*

The final decision: "I basically backed her into a corner, it was the toughest conversation I've ever had with my mother, but it felt like I didn't have any other choice." (386-389) She wouldn't let somebody come live with her (484-485)

“She was very resistant. She wasn’t ready. She wanted to live on her own, she felt like she could. She really didn’t believe there was a problem.” (393-399)

The transition:

Wait list: Had to activate her on the list and wait for her name to come to the top (284-285)

“A familiar face”, not decision maker “compassionate detachment” (663-667, 681-683): Hired caregiver to look after her before the move who helped with the move (366-370) and period after the move (633-635)

The day of the move: Very difficult (378). *DC #5 couldn’t go here, waved me off*

The months after the move: “It’s been a struggle ever since” (407-411)
“She’s waiting for us to come back from our trip so we can plot how to get her out of there together (421-422)

The transition never ends

Frustrating (419)

The negatives: doesn’t like the food, doesn’t like the people, doesn’t like the activities, doesn’t like the isolation so stays in her room (413-420)

Hear about how miserable she is living there and that sort of thing, and just repeat of the conversation all over again (470-472)

Now:

Very anxious, worried about world events and sorts (454-457).

Feels she’s going crazy there (422)

“She knows that she’s dealing with this disease and that she’s not going to get better and that she knows she’s not going to get better and that she can’t live on her own. She just doesn’t want/can’t accept that.” (425-427)

“It’s a real struggle for her” (427-428)

“Doesn’t want to associate with them because most of them are losing their minds” (431-432)

“Maybe a whole bunch of it is you are kind of looking at yourself and it’s pretty frightening.” (440-441)

Emotional turmoil for everybody involved (756-757)

- **The guilt:**

Leaning on friends (674-675)

“It becomes very difficult to be sensitive and compassionate to her needs as you’re trying to make all these decisions and changes for her and she’s very anxious and resistant” (750-756)

“...when you start to hear about how she doesn’t like this or that or the other thing, it makes you feel uncomfortable because maybe you feel a little guilty and you know all those other, you know what I’m saying? So it’s you know, you just replay this thing on an ongoing basis, and it just becomes very wearing and you’ve got to really watch, kind of look out for yourself in terms of all the emotions involved and all that sort of thing, because it just becomes kind of a grind and it starts to eat at you.” (805-814)

- “Often, I’ll come home and say to my wife, “would you call my mom and talk to her?” because I can’t. “(818-820)
- **“I was going freaking crazy”... I couldn’t go down to see her unless my wife went with me...“I needed moral support if nothing else” (756-760)**
- **“It’s been a real struggle” (839)**
- **Frustration:** The relationship with my mother, with most of us was strained, but it wasn’t awful. It’s really frustrating that I don’t see any of them stepping forward to help in this situation, even to the extent of they can’t pick up the phone and check on her. (900-906)

“It’s extremely frustrating, to the point where I don’t have a close relationship right now with a couple of my brothers, and I’m not sure I ever will again, because I’ve become resentful. “

Strategies:

Deflecting

It takes a village:

“There were various friends along the way that helped Mom out tremendously. But we they ended up leaning on them tremendously. They were willing but some of them just flat burned out” (673-675)

She became resentful (felt they were treating her like a little kid) and even though they understood the situation after a while some of them just started backing away (673-693)

People still in her network will pick her up and take her shopping, to a concert, to a play (776-779)

Church group comes in on Tuesdays, his step-sisters are now coming to the Tuesday lunch and occasionally take her out" (781-791)

Choosing the home:

She and her husband had put themselves on the list [for the home] years ago (294-296)

The cats: "She does have two cats, and that was part of why she wanted to stay in the town we grew up in" (443-444). "Those cats are her whole life" (519-520)

She didn't want to leave the town we grew up in (478-479), limited the options

"The other options I looked at were pretty scary" (481-482); what I heard made me uncomfortable (491-492)

"There was the safety net for her health issues" (494-495)

Wanted her up here, because it would be easier for them, but took 1.5 years for her name to come to the top of the list here and then concerned the move would have been way too disruptive for her. Plus she couldn't have her cats here. (500-521)

Had multiple family members there, probably best place in town (522-525)

"Pretty warm, welcoming, safe place. I have felt pretty comfortable with the situation and with the people working there" (526-527)

Greatest hope:

She would have felt more comfortable, quit resisting so much, maybe more involved, be more social, and just that she would become more comfortable there...she's a very anxious person, I don't know that we're ever going to get there (547-554)

Greatest fear:

At the time more worried about whether she was to burn the place [condominium complex] down with herself in it, along with all those other (561-564)

Afraid she was going to turn down the opening (577-578). Had she not moved into the home, I didn't see a lot of other good options, other than moving her up here...and that would have been a difficult situation trying to convince her at the time that that's what she should be doing." (597-605)

Visitation evolution:

Initially visited often, lots of calls to mom and the network on an on-going basis, like having a second job. (717-728)

"I was back and forth for quite a while, then I got to a point where for myself it was extremely difficult to go down there and deal with this situation. It was a lot of stress and a lot of pressure...I got to the point where **I needed support** in the process and dealing with a lot of this sort of thing. (719-726)

Initially. talked every day sometimes more than once. If not to her, to someone that was in her network then. (762-766)

Definitely a lot more contact in the beginning because she could call. Can't make outgoing calls now...forgets she can ask for someone to help her. (822-825)

Unless she's really agitated they're not necessarily thinking, "would you like to call your son today" (825-826)

Now, talk regularly and go down every three months or so (771-772)

Now, try to go down over a holiday and everyone will come together for a meal so we stay connected. (791-794)

Now, talk to her regularly and if not to her to the social worker. The conversations have become more difficult over time because it's harder for her to talk. (800-803) If he can't do it, then his wife does. (818-820)

Don't have to worry: We don't have to worry about not knowing what's going on. They call us. (534-535)

A lot of change:

During the transition from home to ALF:

“The stuff became overwhelming” (734): We were concerned about trying to hold onto family type stuff and making sure we knew the story behind this and that and the other thing...everything had meaning to her, it was special to her

“Spent a lot of time finding good homes for things” (747-748)

Life lesson:

“If I never had any patience before, maybe I’m learning some patience now.” (876-877)

Feeling abandoned:

DC #5: “I have three other brothers, and not one of them has been involved to any real great degree in this situation.” (895-897)

At the end of the day, this is your mother for crying out loud (922-923)

PWD: “Mom talks about this a lot too, you know. “I haven’t heard from the other kids.” “What did I do to drive my kids away? (914-916)

The disease: “She knows that she’s dealing with this disease and that she’s not going to get better and that she knows she’s not going to get better and that she can’t live on her own. She just doesn’t want/can’t accept that.” (425-427)

Descriptive Analysis Memo – DC #6
Pseudonym: Diane and Henry

Kin relationship: Daughter-Father

Age: FCG 55, PWD 86

Stage of dementia: 4

Education:

FCG: Completed high school

PWD: Completed 8th grade

FCG health: Excellent

PWD status: Living

Length of time caregiving before move: Almost 3 years

Quality of relationship: Extremely close

Time since move: 2 years

Durable power of attorney: FCG

AL: Facility, 54 people, approximately 100% with dementia

Distance to facility: 6 miles

Visitation policy: Open

Payment source: Medicaid Choice Waiver

Before dementia: Active and independent

Relationship: Extremely close.

Effect on situation:

A problem: I think it's a problem. I don't know if you're real clear making the best decisions, you're pretty torn (168-170). Dad comes first, instead of what might be best for me or my husband and I. So it's impactful (172-176)

Effect on decision to move: Extremely impactful. He's your dad, and again, he has these clarity moments that I-I can't treat him like a child and quite frankly, I really don't want to face the situation either, but you had to (89-92). Somebody had to put it [the dementia] in my face. I had to acknowledge it...I couldn't pretend anymore (55-58). Talked to his provider and knew I'd have to make a decision eventually. "Literally I looked at little ones and big ones, this and that, and then I must have driven the one I chose crazy. I'd go like six times a day...Can I see this one? Can I see that one? I wanted to be sure it would be just perfect and I had to...it's all fear. We were now changing somebody else's life in a gigantic way (62-68). Dad toured it and I said dad would this be an acceptable home because you can't live alone anymore? And he said, "but, I can" and I said, "no, really you can't". He said, "It's a nice place, but I don't need it yet. Someday, but not today" (82-88)

The impetus: We have to figure out something that I know you're safe and you're happy and if we can make sure you're safe and happy then it's a win-win. (Shared after the tape was off: He wasn't eating anything but cookies, "even if we went out he only wanted dessert", he was wandering the halls in only his robe, he was isolating, he was depressed, he was passing out and falling. I was taking care of his medication, his grocery shopping, his laundry, his finances, going over every day, going to doctor appointments, tried in home help and he fired them or wouldn't let them in, then they tried staying with him, and then took him to her home).

The final decision: I offered him an opportunity, but it never really was an opportunity. It was something that had to be done. Ultimately, it was my choice.

The transition:

The day of the move: Sister flew up. They took him to lunch while her husband moved his belongings into the ALF. Gave him a low dose anti-anxiety medication and brought him to the ALF. He wanted to know why they were there. They told him the loved him so much and "it isn't a drop off, this isn't like we're dropping you off and saying farewell. This is a move that we're all making together, and he said "I don't need this you know, and I don't understand why you would do something like that to me. You know I've always been there for you kids and it's like and [deep exhale] we're here for you, but things have to change, and that's when he had the heart attack." (96-103).

The months after the move: The first nine months were "horrible". March was the first time she left him. "probably the best thing that happened to us because he had to get to know his caregivers and he found that they were rather nice people. Now has his own little band wagon. Makes the rounds. Still doesn't attend social events.

Now: Incredibly changed. Got to know the caregivers, thinks my husband, whom he idolizes, spent a lot of time finding this place, thinks he did a good job. Disease is progressing.

The guilt: "he had just signed that no resuscitation and it was like wholly-smolly, what have I done?"

You never mean to make it about you, but it is a factor too. It's like he would have been real happy and safe in his bed, if I'd left him alone. No, I got to take him to a new place and has a heart attack, that's nuts.

The betrayal: “He just didn’t understand why we would betray him like that” (182-183). Why we couldn’t just make up, let him go home, we’ll forget the whole thing. And why would your own children do something like that to you” (183-186).

Strategies:

Focus on the positives: I’d be all positive (203). He was having nothing to do with it.

Cajoling, being frank, agreeing and trying a different tact

“It takes a village” (562): “He doesn’t need you, he needs a village”

Greatest hope: Partake in activities, be happy he was there, thought if his mind could be more engaged, he could be more engaged (254-257). Realized these were all my dreams and hopes. “He’s still the master of his own destiny”. I have to let him choose, even if it’s not what I want.

Greatest fear: “Everything was my worst fear” (280). My decisions are not just affecting me, they’re affecting someone else.

Visitation evolution: She received no input from the ALF regarding visitation. My sister spent the first week with him and I the second. I slept on the floor because he was afraid. They allow you to come anytime day or night. I like that because then I know how they are taking care of him, not just “cleaning him up for show”. When she first started going, she was going every day and staying. This lasted for about 3 months. Then I had to choose between my work responsibilities and my father and so we had to change. I still went every day, but only for a window. Much more relaxed now. (443-515)

I don’t feel frightened to leave him alone

They are not me: It’s not a 100% (522). I’m nitpicking from the outside (522-523). They all function really well if I just leave the situation alone.

A lot of change: Not only for my dad, but for us too (502-503). “Sometimes it’s like Disneyworld is in my head, he’ll be so happy here...It’ll just be perfect...None of it was perfect. Don’t go in thinking there’ll be rainbows and blue skies, go in knowing that this is a very, very stressful time. And as stressful as it is for you, remember, it’s six times as stressful on your loved one.” (544-550)

The disease: You tell him he’s sick and it’s ok. And he says, give me a pill and that’d make me better. Oh, but wait I forgot to tell you there’s nothing we can

really do, it'll just get worse. Of course I didn't say it like that, but that's the gist of it. You're screwed. You know I'll be here, but this ship is sinking, that's pretty hard. *Want/need control in a situation in which there is no control because somehow it gives hope that they will miraculously get better*

The butterfly effect: A calm and courageousness setting in (582).

Time's a gift: Time eases pain; time's a gift (556)

I'm just proud of dad.

Want to protect him, like he protected us – off tape

Descriptive Analysis Memo - DC #7

Kin relationship: Daughter and Mother

Age: FCG 50, PWD 94

Stage of dementia: 6

Education:

FCG: Completed high school

PWD: Completed 8th grade

FCG health: Excellent

PWD status: Deceased

Length of time caregiving before move: 4 years

Quality of relationship: Close

Time since move: 2 years

Durable power of attorney: FCG

AL: Facility, 5 beds, 100% but unsure about 1 person

Distance to facility: Less than one mile

Visitation policy: Open except in the evening

Payment source: Medicaid Choice Waiver

Before dementia:

Outgoing, liked to talk and loved people, sang all the time, really involved in church, pretty much what you saw at her older age is what she was when she was younger, very nice and compassionate and just probably 60 to 70 percent more of what you saw as she was declining. Strict. She didn't change her mind very often. She was a lady. (224-247)

Relationship

How affected CG during transition: "It affected me greatly because I probably wouldn't have moved my mother at all had I not been on my last rope." (298-299)

Coming to the decision: Going down that journey of wanting to and not being able to and trying to work it all out (360-362)

My kids were being affected more (300): I was taking my frustration out on them (362-383)

Every attempt made was thwarted: I had plastic everywhere to catch everything. She was leaving even though I had every device. She'd spit out the medicine to help calm her when she was agitated. She'd be up to 2:00 or 3:00. I'm back up at 6:30 in the morning with my kids. I hid shoes. I hid slippers. I hid coats. I hid everything. She'd walk out in the snow with her socks on. (301-351)

Not sleeping, couldn't go anywhere, I couldn't leave her, she escaped while I was gone one day (331-341)

"I couldn't live with her walking out in the wintertime" (347)

"That's when it started becoming that I knew that I needed to (pause, not finished) (343)...It was just too much" (345)

The final days/I was spent: I think I was laying upstairs in bed. And I said, “God I don’t want to take my mother and put her any place, but I can’t do this anymore. I’m losing myself. I’m losing who I—do you want me to live?” (387-390). I remember hanging on a string and saying, “I need a place that she can go.” I got up and I went and I knocked on that woman’s door again and I was like, “I need a place for my mom. Do you have a room?” She said she’d just got a room. “If you want the room, you can have the room.” I said, “I want the room today.” (394-405)

Choosing the Home:

Familiarity: *Easing the transition* Small like my home (406), built the same year, kinda had the same feel, it was familiar (406-423). “I felt good about that” (427). The smell of food (1537-1538)

Proximity

Highly recommended: The woman who lives on the same street as my sister ranted and raved about it

“She had her own bedroom” (543-544)

I was spent: “Because I was at my end at that point, I didn’t have any energy to look for an assisted living home. I didn’t have any energy to look for anything. I just went on to knock on the door. That was my beginning. To just I need a place for her. I’m tired, now. I need to and she said I have a room. Praise God.” (1497-1505)

Easing the transition:

Pointing out the positives: “You’ve got your own room”

Making it familiar: “I took all of the pictures of everything. I set that room up as much as I could as would be her room. I took her hats over there. She loved her hats. I made that room look like it was her room. (548-552)

She had a window to look out of: She had the exact same window at our house that her husband built for her. (928-929) It was very familiar (935).

The “mothering instinct” (575-76): Are they taking care of her right, looking for something, I’d clean her to be sure her skin is good and she’s bathed properly, “you have my kid and are you taking care of my kid?” I would show up times that they weren’t expecting me. I checked behind her ears, checked her feet. “Stand up and let’s walk. You ain’t walking enough.” The couch needed to be replaced so they could get off it more easily (897-899). Nothing was quite good enough (899)

I was trying to keep her alive (976-977): I’d take food over: Even at the last when I was doing that, I think when I was doing that it was more for me. (850-851) I was trying to get my mother to stay alive. *I wasn’t ready to let her go.* “Do you understand life? Don’t go to sleep.” “And you’re going to leave here” (976-990) *If only you’d get better, I could bring you home.* “I think somewhere in the subconscious there was a place where “you’re gonna live forever and you’re going to get better.” (989-990)

“Looking for control in the storm”:

Making her feel special: Got flowers every week. She'd get something special. (187-191)

God's grace to save me: I knew they were keeping her clean. I knew they were feeding her (839-840). They were nice enough to let me be comfortable enough doing what I did with my mother. (868-870)

The emotional turmoil: Because I couldn't do it and I wanted to (447)

The Day of the Move: It was hard (435): I bawled like a baby. I bawled like a big baby. And I kept bawling like a baby because I would go see her and she'd be like, "when are we going home?" (435-438)

The turmoil continues:

[I'd] walk out the door and I bawled like a baby (446). I'd drive by and I'd bawl like a baby (446-447)

The guilt: I felt like I was just tossing her off, but I wasn't. I was just giving her to someone that could take care of her better than I could (451-452). It's like a 12 year old mother who gives her baby to some adult to take care of. (455-456)

The guilt was larger than the fact that I couldn't take care of her alone. "I carried the whole load" (476-477) (454-480)

Knew it wasn't her house: "Aren't we going home?" (136, 139). She knew that wasn't where she should be. (143)

Where's my family: About 5 months into the move she asked her what was the matter. She said, "What you think?" "These people, they with their family. I have a family." (589-593). She basically just said to me, "I'm feeling like I have a family that I can be with and I'm not with them." "That day was terrible for me." (632-635) I tried not to cry because I didn't want her to know that I understood what she was saying, but I got in my car and I just sat and I wept (644-646) That was hard. That was a hard day. That was a really hard day." (690-691)

Redirecting/deflecting: It was really hard. I felt like I was lying to her (145-146)

It was hard: "It was very, very hard. It was the hardest thing I think I've ever done, and I've done some hard things. But literally, I think having babies was easier than dropping your mother off. Just it was hard. I can't think of anything harder that I've experienced where I just – because there's such a connection already."

“Here’s the person that has raised you and brought you to the place that you’re at. And now they’re needing you to take care of them and you’re incapable of doing it? What is that?” (495-498)

I had gotten to the place where my faithfulness had ended and God was allowing for someone else’s faithfulness to kick in and finish (499-501)

“I think the reason why I hadn’t moved her sooner was because of that emotion” (536-537)

“Every time I’d come, she’d grab her purse. She was like “Okay. We ready to go?” (665-666)

The transition never ends:

Mom never settled: Even to the last, she would say, “Oh, are we going? Am I coming with you?” And she’d grab her purse. “We getting ready to go?”

“I didn’t ever get used to it.” (882)

“The protective eye” (1039): God never allowed me to see this – you know, the paper – what stage – I never saw – I never read the last page. (1032-1034). “You know you sit and read a book and go, okay. Chapter one is about this, chapter two is about this and chapter five” I was at – we’re at chapter two. We’re gonna stay at chapter two. (1048-1050) And even though I’ve read the whole book – I didn’t – consciously wasn’t allowed to grab it all. I just think that it would have been...too much. The end wasn’t in view, only what I had to deal with at the moment. (1048-1062)

Visitation: Open except at night. Couldn’t go in the evening when she first moved in because it was too disruptive to Mom (69-71). Then never took her out after 5pm.

Ever vigilant: The initial transition: During the first 2 weeks, I would spend the night in the chair in the living room or I’d spend it in her room. I’d sit in the chair and watch her breath. Then I’d come out and sit in the chair in the living room and would sit for a couple hours and then I would go back and say, “I’ll see you later. I’ll see you in a few hours.” And I’d come home and or I’d go do something and then wash up, clean up, say hello to my family and go back over there. (85-93)

Visitation evolution: 2-3x/week (105-109)

More harm than help: After 5:00, it was kinda settling down time, and so if I was to come in and disrupt and take her out at 7:00, which they let me

do a couple times, I realized it was best for mother. Took her a long time to settle down...she'd want to come home with me. (118-126) So I stopped. It was really hard (128-129)

Giving up a part of her (130)

She wouldn't understand: If I said, "Mother, I'm not gonna bring you back here to the house. You're gonna have to stay here because I can't take care of you anymore. It's just too – too much for me." Then she wouldn't have been able to comprehend that.

Staying connected: It kept me from forgetting (211-216): "I still picked up all her meds and did all that. That gave me an opportunity to still stay connected to her." (195-196, 220). "I wasn't really really wanting to relinquish so much so that I would – it's just like you forget about that you have a mother around the corner" (211-214)

I was grateful: She kept a part of herself. "You're not going to do whatever you want. I'm still here." (276-277)

I'm grateful: I had the opportunity to do as much as I could. (1095-1096). I was still able to continue the relationship even though it was what it was (1124-1126). "Being able to bring her up here and her spending the last years of her life here with me was a gift. It was a gift, but I didn't know it was a gift at the time. But it was a gift. It was a great gift." (1167-1176). We'd go to church and hold hands the whole time and smile at each other. It was God giving me a gift, and I'm grateful. (1224-1246). I got to reap a wonderful reward before he brought her home (1250-1251)

I don't have any regrets (1184):

I wish I didn't have to move her but the place that was provided was a great place, in retrospect. They loved her (1184-1186).

Greatest hope: That she would get better and she could come back here and live with me or I'm gonna get better and she would get to come back home" (696-707)

Greatest fear: That they would not take good care of her, but she would be there if I didn't think they'd take good care of her.

The respite homes:

The great escape: She was gone 2-3 hours before they knew she was gone. Fed her ramen and bologna sandwiches, didn't cook there
Sterile, no warmth

Mission of AL: “feed, clothe, bathe, sleep, feed, clothe and that was all that they were - really had to do” (940-945).

Lesson:

The things that I learned from her, because she was still teaching me: love, patience, long suffering, gentleness, goodness, faith. God allowed me to learn them. I need the grace and the patience to learn. (1581-1596)