# ABSTRACT

# THE IMPACT OF TRANSITIONING TO AN ASSISTED LIVING FACILITY FROM THE PERSPECTIVES OF FAMILY CAREGIVERS

By

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The purpose of this study was to explore the decision making of family caregivers who were considering transitioning an older adult family member from independent living to an assisted living facility (ALF). A total of 15 caregivers were interviewed**;** 12 (80%) decided to place the older adult in an ALF and 3 (20%) decided not to do so.

This study found that the decision to place an older adult in an ALF was primarily due to the declining health of the older adult and safety concerns. All of the 12 caregivers who placed their family member in an ALF reported that they continued to be involved in caregiving after placement. Caregiver support groups and self--care were two interventions that participants described as most effective to support them during their caregiver experience. More research is needed on how to support family caregivers who are considering placement in an ALF.

# THE IMPACT OF TRANSITIONING TO AN ASSISTED LIVING FACILITY FROM THE PERSPECTIVES OF FAMILY CAREGIVERS

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# CHAPTER 1

# INTRODUCTION

## Problem Statement

As the life expectancy of the United States population continues to increase, so will the number of older adults who will need to relocate to assisted living facilities. Due in part to improvements in medicine, technology, and health that are facilitating greater longevity, and with the "baby boomers" reaching the age of 65 years, the older adult population has experienced tremendous growth that has resulted in an increased demand for assisted living facilities (Blow & Barry, 2012; Shippee, 2009).

In 2012, the proportion of those 65 years of age and older was 13.7% of the United States population (U.S. Census Bureau, 2013). By the year 2030, this percentage is expected to increase to 20%, with nearly 71 million older adults living in the United States (Smith, 2007). The oldest-old, those over the age of 85, are the fastest growing age group (Smith, 2007). The number of ethnic minority older adults living in the United States is projected to increase with Latinos, Asians, and African Americans as the fastest growing racial groups (Braun, Ford, Beyth, & McCullough, 2010; Ivey et al., 2012).

The majority of older adults would prefer to remain living independently in their own home for as long as possible and consider independent living as being able to live in one's own home and being in complete control of one's environment (Levy, 2010).

However, with increased age comes an increase in chronic or acute illnesses and diseases, which makes it difficult for older adults to maintain their independence.

When older adults can no longer live independently and care properly for themselves, family members, typically adult children, will often step in to care for their older adult parent (Bookman & Kimbrel, 2011). Often with time, according to Gaye (2010), caregivers commonly become at risk of harming their own emotional and physical well-being due to the stress and the intense demands associated with caregiving, especially when the older adult suffers from a progressive condition. The struggle of balancing jobs and attending to their own family needs, all while providing care for an older adult with declining health, can eventually lead adult children to consider alternative means of care, such as assisted living (AL) placement (Gaye, 2010).

In 2009, it was estimated that there were more than 900,000 older adults placed in assisted-living facilities (ALF; Shippee, 2009). ALFs are regarded as residences designed specifically for older adults and are considered midway between living at home and living in a nursing home (Kelsey, Laditka, & Laditka, 2010). The cost of ALFs can range anywhere from $800.00 to $4,000.00 a month, depending on the types of services provided and needed. It is noted that 80% of residents entering into ALFs are homeowners. Of these 80%, 79% pay for their monthly placement expenses using private funds (Andrews, 2010). Hence, it is often common for homeowners to sell their homes during their transition to be able to cover the costs of their new living arrangement.

ALFs are not evenly distributed throughout the nation. The states with the highest number of ALFs include California (with 15.7%), Florida (6.1%), and Texas (4.5%), which are not necessarily states that are considered to have the highest population of older adults; those states are Florida, West Virginia, and Maine (Andrews, 2010).

With the recent growth in the numbers of older adults on a national level, there has been considerable scholarly research conducted on the older adult population and on caregiving. There are nonetheless, few studies that have specifically focused on the needs of family caregivers who are considering placing an older relative in an ALF.

## Purpose Statement

This research aimed to better understand the impact of transitioning to an ALF from the perspectives of family caregivers. Specifically, this study sought to answer the following questions:

1. What were the circumstances that led caregivers to consider an ALF for their older adult family member?
2. What was the caregiver's level of involvement following ALF placement?
3. How can professionals better assist older adults and their family members with the transition to an ALF?

## Definition of Terms

*Assisted living facility (ALF):* A licensed, registered, certified, or regulated residential setting that provides assistance in personal care, daily living activities, or health-related services to older adults (Allen, 2012; Pruchno & Rose, 2000; Zimmerman & Sloane, 2007). The primary goals of ALFs are to provide 24-hour care services that maximize residents' dignity, autonomy, and independence (Stevenson & Grobowski, 2010). Although AFLs vary, most provide options in living arrangements ranging from a shared room to a full size apartment (Levy, 2010; Washington, Oliver, Demiris, Wittenberg-Lyles, & Shaunfield, 2011).

*Caregiver:* A person providing attention to the needs of others, especially to those who are unable to look after themselves adequately (Hermanns & Mastel-Smith, 2012).

*Caregiver burden:* A multidimensional construct producing negative responses to perceived stress as a result of caring for an ill individual, that has the potential of impairing physical, emotional, psychological, social, financial, and functional health of caregivers (Beinart, Weinman, Wade, & Brady, 2012; Kim, Chang, Rose, & Kim, 2011).

## Social Work and Multicultural Relevance

The number of people moving into ALFs will continue to increase as more baby boomers enter older adulthood. In order to develop relevant interventions, social workers need to become more aware of how older adults and their family members cope with the transition to the ALF environment.

Because of the growing diversity of the United States, minority groups are projected to constitute almost half of the population by 2060 (Engstrom, Tappen, & Ouslander, 2014). The level of caregiver burden has been found to differ by ethnic groups (Cahill, Lewis, Barg, & Bogner, 2009). To date, very few studies have examined ethnic differences regarding the decision to place an older adult in an ALF.

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# CHAPTER 2

# LITERATURE REVIEW

## History of Assisted Living Facilities

To understand the beginning of ALFs, Warren (2012) explored the history of ALFs and found that they date as far back as 1489. Warren described the philosophy of aging in residential care in pre-modern times. She identified that the Roman/Byzantine Justinian Code established a Civil Law dictating the basic design of residential care for older adults. Interest in the process of aging from a scholarly and medical perspective was reignited in the early Renaissance area, following a brief cessation in the Dark Ages (Warren, 2012). ALFs were designed with the primary purpose of protecting the elderly from harm, preventing premature death, and extending services so that older adults may live the remainder of their years as peacefully as possible. Assisted living, in its earliest years (during the Middle Ages), served only older men. Those most likely to seek placement into these facilities were rich elderly men, politicians, knights, and monks (Warren, 2012).

The specific locations of early ALFs were intended to maximize residents' health, and it was believed that such facilities should not be in any region surrounded by high mountains or in low valleys where a change of air is difficult to obtain (Warren, 2012). The interior designs of ALFs were to be clean and elegant with proper heating and cooling systems. Windows were designed to be facing the sun, dwellings were bright with wood-plank flooring, and fireplaces were placed throughout the facility. There were set expectations as to the level of care residents received whereby schedules of sleeping and eating were rigorously followed. Proper nutrition was taken seriously and wine was served during meal consumption. Sexual activity, however, was not allowed due to pre-modern beliefs that regarded sexual behavior as an activity strictly reserved for the young. Staff members were carefully selected and chosen for having extensive experience, being sympathetic, having physical strength, and being knowledgeable in treating dementia-like conditions as they were also expected to be cheerful, clean, and well dressed so as to appear pleasant to the residents (Warren, 2012).

Licensing requirements have since changed the organization of ALFs in the United States. Due to the growing numbers of older adults over the past few decades, there has been an increase in the numbers of older adults living in ALFs. Currently, there are over one million individuals residing in ALFs in the United States (Kemp, 2008). These facilities are most appropriate for older adults who are no longer able to conduct their activities of daily living (e.g., bathing, dressing, personal hygiene) or their instrumental activities of daily living (e.g., medication management, meal preparation, laundry, using a telephone; Kemp, 2008; Kim et al., 2011). Some older adults reportedly decide to move to an ALF because they have a health condition they anticipate will worsen and would rather live in an environment that can accommodate a decline in their health status (Koenig, Lee, Macmillan, Fields, & Spano, 2014).

## The Burden of Caretaking Experienced Prior to Assisted Living Transitions

Kim et al. (2011) studied the predictors of caregiver burden on those providing care to older individuals with dementia. *Caregiver burden* was identified as perceived stress resulting from caring for an ailing individual. This study gathered data using a standardized questionnaire administered to 302 caregivers of individuals with dementia or dementia-related conditions. The results indicated that burden was significantly highest among caregivers who were older, female, a spouse of the care recipient, and living in the same household as the care recipient. The most significant predictor of caregiver burden was the functional decline of the care recipient. An unanticipated finding was that caregivers who used more coping strategies were found to have higher levels of burden than those utilizing a minimal amount. Kim et al. found that having multiple caregivers in assisting an older adult did not decrease caregiver burden significantly, which was originally thought to be the case. Kim et al. concluded that more research is needed on caregiver burden.

Cahill et al. (2009) examined burden among those family members caring for an older adult prior to transitioning to an ALF. Fifty semi-structured interviews were conducted with older adults and their caregivers, of whom, 34% identified themselves as Black, 65% White, and 1% self reported to being part of another ethnic group. The term burden was identified in three conceptualized ways: (1) not wanting to complicate the busy lives of loved ones, (2) guilty feelings about health problems, and (3) a concern that loved ones were excessively worried about their health. In comparing Whites with Blacks, Cahill et al. found that White older adults were more likely than Black older adults to mention burden in respect to family involvement in care. White participants, for instance, reported that although they would like to see their adult children more often, they understood that their children had their own lives and responsibilities that took precedence over caring for their elder parents. A recurring theme in respondents that were Black was the perception of older adults as caregivers to their children and not in the reversal of roles. Both ethnicities reported expectations of having their children visit more regularly and perhaps provide temporary assistance as needed, but would not want them to make adjustments to their schedules in order to do so. Older adults who mentioned burden were also those who had low physical functioning and as a result, received considerably more levels of care from family members (Cahill et al., 2009).

Garlo, O'Leary, Van Ness, and Fried (2010) assessed caregiver burden in their study consisting of 179 caregivers and older adults with chronic obstructive pulmonary disease (COPD), heart failure, and advanced cancer. Garlo et al. found that although most caregivers reported to being in good or excellent health, and that they had sufficient emotional support, most had concerns regarding communication between themselves and the older adult, whereby they felt the need to discuss the illness to a greater extent. Caregivers providing care to older adults with heart failure were more likely to report needing additional help with daily tasks (23%), in comparison to patients with cancer (9%) or COPD (11%). Of the older adults that were assessed, 78% reported three or more instrumental activities of daily living (IADL) disabilities, 67% indicated fair or poor self-rated in health, and 50% reported depression. Caregivers who reported helping out more with activities of daily living (ADL) were found to have a higher level of caregiver burden (Garlo et al., 2010). No significant difference in caregiver burden was found based on the diagnosis of the older adult.

J. W. Brown, Chen, Mitchell, and Province (2007) sought to gain an understanding on the help-seeking process of older husbands caring for their wives with dementia. Nine White husbands participated in non-structured interviews. J. W. Brown et al. found that all participants sought additional support from others, such as having a daughter move in or relying on relatives, friends, neighbors, and formal services to assist in caring for their wives. One-third of the participants used a support group, while the rest of the participants refused to seek additional supportive services due to previous negative experiences with care providers. The researchers concluded that several factors can impede the help-seeking process for husband caregivers, including costs, lack or inadequate knowledge of resources, and previous negative experiences with service providers. The help-seeking process for husband caregivers was facilitated as a result of having positive experiences with service providers in the past (J. W. Brown et al., 2007).

## Considering the Transition to Assisted Living

In an attempt to understand the course of an ALF transition, Koenig et al. (2014) explored the perceptions of older adults and their family members who were involved in the decision-making process of assisted living placements. This qualitative study included 22 dyads, consisting of older adult residents and one of their family members. Using semi-structured interviews with open-ended questions to interview both older adults and their family members, findings were analyzed and grouped into three possible categories: congruent, dissonant, and complementary.

Of the sample population, seven of the 22 dyads were deemed congruent, meaning that both the older adult and the family member were accepting of the reasons to transition to an ALF. Eight of the 22 dyads, classified as the dissonant group, indicated disagreements in their understanding of the decision making process, as evidenced by minimized or contradicted perceptions. The final group, the complementary narratives, were found in seven of the dyads, in which partial information shared by one person in the dyad, that when combined with the other person in the dyad, provided a more complete understanding of the transition process.

Koenig et al. (2014) found that older adults and family member dyads described their personal experiences in deciding on a specific ALF in two distinct ways, that of having either a logistical or an emotional component. Logistical aspects included concerns regarding services provided by the facility, costs, waiting lists, and geographic location. Emotional dimensions involved emotional stress, concern for the older adult's safety, coping with older adult's loss of independence, and conflict among family members. Those dyads with more congruency with the emotional dimensions were found to be most successful in managing the transition to the ALF.

A study by Kelsey et al. (2010) considered the perspectives of 15 caregivers of older adults living with Alzheimer's or other dementia disorders who were in the process of transitioning from home to an ALF. This study explored the reasons for moving from home to an ALF and the emotional experiences involved in selecting a particular facility. This study followed participants as they move from an ALF and subsequently, to a memory care unit (MCU) and included caregiver reactions to these transitions.

Kelsey et al. (2010) found that most caregivers ($n = 11$) reported that the decision to place into an ALF was due to concerns with safety and functional decline, with more help needed with ADLs (e.g., meal preparation, medication) and IADLs (e.g., bill paying). Those who were a spouse reported higher levels of burden and described the move to an ALF as more emotional compared to adult children. Proximity to the caregiver's home was a primary deciding factor in selecting an ALF (Kelsey et al., 2010). Because this study also focused on the transition from an ALF to an MCU, 15 caregivers who anticipated the need for specialized dementia care for the older adult were also interviewed to capture this transition. Half of the caregivers interviewed thought that the specialized services would be provided in the ALF as needed, not in the MCU (Kelsey et al., 2010). Kelsey et al. reported that over half of the caregivers described the move from an ALF to an MCU as a traumatic experience. Spouse caregivers who had been married for many years stated that the move from home to an ALF was considered more traumatic than the move from an ALF to a MCU. Adult children, in comparison, considered the move from an ALF to a MCU as more traumatic compared to the move from home to an ALF (Kelsey et al., 2010).

### Special Circumstances Regarding Assisted Living

Morgan and Brazada (2013) conducted a qualitative study by interviewing 77 adults in AL settings which included family members, facility staff, and administrators to examine the transfer of autonomy over life tasks (e.g., money management) due to functional and health decline on behalf of the older adult. The sample population was predominantly female (70.1%) and White (85.7%), and over half (58.9%) had attained an educational level beyond high school. Most participants chose to move to an ALF to avoid moving in with their adult children, not due to strained relationships but as a way of exercising positive control. The older adult’s declining capabilities were described with intense emotion.

Morgan and Brazada (2013) found that there were variations regarding the older adult’s level of acceptance of their physical limitations whereby some for instance, had demonstrated proactive planning for their later years. In describing their decision to designate a proxy to handle personal matters, six of the older adults reported positive reactions about the person chosen as the transfer of control. Nine described the transfer of control as being taken by another against the will of the older adult. Of these nine individuals, seven described this experience in a negative tone, while the remaining two spoke about this experience in a positive manner. Morgan and Brazada concluded that the process by which the transfer of control shifts to another person plays an important factor in psychosocial outcomes, more so than the actual decline in personal autonomy.

Kemp (2008) conducted an exploratory study on married couples living together in an ALF and how this arrangement influenced their adult children's level of support from the perspectives of spouses, adult children, and administrators. Ten adult children, representing eight couples, along with eight married couples residing in an ALF, participated in semi-structured interviews, which were subsequently interpreted to identify unique experiences. Adult children reported difficulties in being able to support the needs of the couple collectively. A couple's needs were ultimately determined by the one in poorer health and the need for both parents to relocate due to the desire to keep the couple together. Challenges arose in finding a suitable placement that would benefit the individual needs of both parents. Kemp found that most ALFs were best suited for individual residents, but not so well for married couples. In searching for a proper placement for the couple, some adult children found facilities willing to accommodate both parents, but for a substantially higher price (Kemp, 2008).

Even upon placement, Kemp (2008) found that adult children continued to provide support to parents in various ways, such as managing financial matters, advocating for additional services as needed, and monitoring the health of their parents. Kemp also found spousal caregiving in an ALF to be risky. For example, Kemp reported that a wife who had been assisting her frail husband in showering had one day fallen and injured herself. While spousal caregiving in ALF can be problematic, Kemp noted that the benefits often outweigh risks because it promotes ongoing closeness within the couple.

In understanding a different perspective regarding ALFs, Stevenson and Grobowski (2010) used primary data collected from the Online Survey, Certification, and Reporting (OSCAR) system for nationwide Medicaid and Medicare facilities. Stevenson and Grobowski discovered that many of the ALFs nationwide are disproportionately located in areas with higher educational attainment, higher income levels, and with greater housing wealth among local residents. In other words, minorities and those of low-income have considerably less access to ALFs as a care option. Additionally, hindering potential access to AL is that Medicaid does not pay for beneficiaries' room-and-board expenses, which are typically covered using the residents' income, private pensions, Social Security, Supplemental Security Income, state supplements, and federal housing subsidies.

Stevenson and Grobowski (2010) reported that the quality of care within ALFs is difficult to measure since ALFs, unlike nursing homes for example, are not federally regulated. The services provided by each facility vary due to the degree of government involvement regulating the types of services that should be made available to residents. Stevenson and Grobowski concluded, that in order to meet the growing demands of the aging population, changes in policy need to emerge to better prepare for the increased needs of older adults across all types of long-term care settings.

## Psychological Impact of Caregiving and Assisted Living

Daire, Torres, and Edwards (2009) conducted a review of literature regarding the psychosocial impact and clinical needs of caregivers of individuals with dementia. Daire et al. found that caregivers of a person with dementia, whether living independently or in an ALF, placed caregivers at risk of psychological distress, chronic fatigue, and feelings of anger and depression. Daire et al. reported that spousal caregivers assumed the role as the primary caregiver and sustained the greatest challenges as a result of directly witnessing a loved ones intellectual and psychological decline, and because spousal caregivers tended to be older than other types of caregivers, they often experienced a decline in health conditions that may have worsened or developed as a result of caregiving. Spousal caregivers were also more likely to have presented with higher levels of stress and depression, lower levels of life satisfaction, and a decrease in social activities when compared to adult children caregivers. Daughter caregivers were also found to have experienced negative effects in areas of health, family life, and work responsibilities. Daire et al. suggested further research on the impact of sons as caregivers.

Liken (2001) studied the impact of moving a relative to an ALF using secondary data analysis on 20 face-to-face interviews with family caregivers. Participants' ages ranged from 38 to 83, all of who were White, and had assisted a relative with Alzheimer's disease within the past 6 months. Liken suggested that facility placement of a family member was done only as a last resort and usually resulted from caregivers experiencing a crisis, defined as a turning point occurring as a result of presented obstacles that are important to life goals. Most of the caregivers reported uncertainty about their decision to transition their family member, along with reported feelings of guilt and a sense of failure.

Liken (2001) found that of the 20 participants, five caregivers experienced resentment of family members and also reported disappointment with health care providers. Nine participants mentioned the cost of AL, and concerns over the unanticipated decline in the cognitive state of their family member as negative outcomes of the transition. Despite these negative outcomes, Liken concluded that there were positive aspects reported by 15 participants, which included being able to resume their lives and not having to constantly worry about caring for their family member.

Cruz (2006) conducted a study using ethnography methodology to gain an in-depth understanding of resident's and their family caregivers' experience with placement into residential care. The researchers used observations on eight residents and semi-structured interviews on six family caregivers to gain individual perspectives. Participants were gathered using purposive sampling from an ALF located in what was described as a coastal southern state. Cruz discovered that ALFs that encouraged residents to maintain their self-care habits had a positive impact on satisfaction with care. Caregivers who wanted to maintain some caregiving duties, such as assisting with dressing or meal preparation, were disappointed to discover that that the facility would not accommodate them due to routines and other confines structured by the facility. Many caregivers reported feeling displeased that they did not have a proper place in the unit during visitations and also expressed interest in the ALF providing more opportunities for family members to be involved in activities with residents, such as going on outings (Cruz, 2006).

Washington et al. (2011) performed a study on end-of-life care in adult family homes (AFH), which are a type of hospice care designed for terminally ill older adults. Semi-structured interviews were conducted with 15 family members who had placed an older adult in an AFH. Most family members described the decision to place their loved one in an assisted care facility as an extremely difficult and emotional experience. However, Washington et al. also reported a high level of satisfaction with the care their older adult relatives received by the AFH staff. Respondents strongly emphasized the importance of good communication between AFH staff, patients, and family member(s) as being a critical component in assuring high quality of care.

## Interventions

Hudsen et al. (2013) introduced two versions of a psycho-educational intervention in a study aimed to prepare family caregivers of patients with advanced cancer. The primary purpose of the intervention were to reduce psychological distress, decrease unmet needs, and better prepare family caregivers for their role in caring for a family member with an advanced stage of cancer. The sample consisted of 298 participants. A total of 57 caregivers were given Intervention 1, 93 were given Intervention 2, and the remaining participants were in a control group. Intervention 1 consisted of a one-time visit, whereas Intervention 2 included two visits. Hudsen et al. found no significant differences by gender in their preparedness for caregiving and concluded that older participants were better prepared to be caregiver than younger participants. Hudsen et al. found that although Intervention 2 (two visits) produced more favorable results than Intervention 1 (one visit), neither significantly improved the psychological well-being of caregivers. They determined that more research is needed on effective interventions for caregivers.

Beinart et al. (2012) performed a review of the literature to examine caregiver burden when caring for patients with dementia, specifically Alzheimer's disease and the effectiveness of available interventions to reduce burden. Factors leading to higher levels of caregiver burden were older age, lower socioeconomic status, inadequate social support, problematic family relationships between caregiver and care recipient, and insufficient coping strategies on behalf of the caregiver. In comparing genders, Beinart et al. found that male caregivers were prone to physical illnesses, whereas females demonstrated more psychological symptoms, such as loneliness and depression. In reviewing 35 studies, the researchers suggested that the best approach was problem-focused coping strategies to alleviate the burdens of caregiving. Beinart et al. recommended that psychosocial education should focus on skills training tailored to the behavioral problems of the care recipient associated with the disease, decision-making strategies related to the management of the disease, the emotional consequences of being a caregiver, and the promotion of effective self-care habits.

Robinson, Pesut, and Bottorff (2012) recruited 23 participants in their study aimed at exploring the needs and how to effectively support the well-being of rural palliative family caregivers. Robinson et al. discovered that these participants were so immersed with their caregiving efforts that they rarely attended to their own self-care. In attempting to identify the needs of caregivers, Robinson et al. constructed four themes based on the data provided: (1) the need to be a palliative caregiver, (2) the need to become skillful and knowledgeable, (3) fulfilling the older adult's needs, demands, priorities, and desires, and 4) the need for additional support.  Participants spoke of a lack of preparation by health care professionals as to what being a caregiver would entail. Although the need for additional help was evident, at times primary caregivers had difficulty asking for assistance and in accepting help.  Robinson et al. concluded that health providers needed to educate family members on the requirements of caregiving and in the importance of developing better interventions to support caregivers.

## Multicultural Perspectives on Assisted Living Facilities

Ivey et al. (2012) examined the perspectives of Filipino and non-Hispanic White caregivers and their experience of caring for older adults with dementia.  A qualitative approach was used in the nine cross-cultural focus groups, consisting mainly of women, where differences in experiences and perceptions were found when comparing the two ethnicities.  White caregivers for instance, were more likely than Filipino caregivers to report feelings of guilt over wanting time to themselves when feeling overwhelmed. White caregivers tended to discuss concerns regarding a decrease in social interactions as a result of caregiving and felt that others did not understand the demands in providing care to someone with dementia.

Ivey et al. (2012) also found that Filipino caregivers often described their caregiving experience as a learning opportunity and how caregiving made them a stronger individual.  The Filipino group often perceived family members involved in caregiving as being good or saintly individuals.  Ivey et al. concluded that although both ethnic groups reported positive and negative aspects in their experiences, significant differences between the two ethnic groups were found in held perceptions, behaviors, and experiences.

S. H. Brown, Herrera, and Angel (2013) studied 628 Mexican American women and 391 men from five southwestern states to examine gender-based risks associated with an older adult parent not entering long-term care facility as a result of opportunity costs. Opportunity costs were referred to as wages lost by adult children due to time commitments spent on caring for an adult parent, including time used on driving to and from the older adult's residence, and whether caregiving could be shared amongst other siblings. Elderly parents' levels of care needs were found to be strongly associated with the decision to place them in a long-term care facility among Mexican-American families.

S.H. Brown et al. (2013) found that for Mexican-American males, spousal caregiving was more common than caregiving by adult children. Mexican-American older adults who were female relied more on adult children, particularly female adult children, for assistance. Older adult females were also more likely to be living with or within close proximity to an adult child in comparison to males. S.H. Brown et al. concluded that as the severity of the older adult's disabilities increase, so will opportunity costs, regardless of gender, implying that high disability rates lead to an increased risk of entering into long-term care.

Carrion, Park, and Lee (2012) examined the use of hospice care in Florida in their study using a sample drawn from a database consisting of 22,936 patients. The sample included 80.6% who identified as White, 9.6% were Black or African American, 9.3% were Hispanic, and 0.5% were Asian American or Pacific Islander. The purpose of the study was to understand the underutilization of available benefits of hospice services among racial and ethnic minorities at a national level.

Carrion et al. (2012) found that in regard to gender, hospice care was most utilized by females among all four racial/ethnic groups. Ethnic groups demonstrated differences in patterns of caregiving. Spousal caregivers were more common among Asian/Pacific Islanders (36%) and Whites (35%). Representing the second largest group of caregivers among Asians/Pacific Islanders, were sons, as daughters were for Whites. Among Hispanics, both spouses and daughters accounted for the largest group of caregivers. African Americans reported 41% of the use of "other" caregivers.

C. M. Brown and Gibbons (2008) explored the psychological well-being of American Indians in an ALF in the United States. The sample included a total of 56 tribal member elders. C.M. Brown and Gibbons found that residents reported satisfaction with the facility staff as suggested by positive comments in regard to the quality of service provided. Residents reported they felt that having the support of other tribal members within the facility made a huge difference in which many reported they felt their lives were better at the facility than when they were at home. Residents reported feelings of loneliness were prevented by activities and health services made available by the facility, where most residents took the opportunity to attend meetings that served as a means of socialization. C. M. Brown and Gibbons suggest further studies on the transition to an ALF to better understand how the moving experience impacts residents overall.

Oliveira et al. (2013) studied the prevalence of caregiver role strain, defined as a difficulty in caring for a family member, similar to the meaning of caregiver burden, by conducting a cross-sectional study in North-Eastern Brazil, which included 42 caregivers of patients who had recently experienced a stroke. Ninety percent of the participants were women, 45.2% were daughters of the older adult. Forty percent stated to have left their regular jobs to assume the role as a caregiver, whereas 20% were retired. Oliveira et al. found that 73.8% of the caregivers reported experiencing role strain.

## Conclusion

There are many studies that have found caregivers are at risk for psychological distress and physical health problems. An older adult's loss of ability to perform ADLs and functional decline placed them at risk for an ALF placement (Kim et al., 2011). Females continue to constitute the majority of family caregivers (S.H. Brown et al., 2013; Carrion et al., 2012). Many families rely on spouses and daughters to assume the role of caregiver, and without their much-needed assistance, the ability for ailing older adults to remain at home often becomes impossible (S. H. Brown et al., 2013; Carrion et al., 2012). When caregivers do experience high levels of burden, many still do not seek supportive services (J. W. Brown et al., 2007).

There are gaps in the literature regarding the impact of transitioning an older adult to an ALF. Based upon the current review of the literature, this study aimed to better understand the impact of transitioning to an ALF from the perspective of family members.

# CHAPTER 3

# METHODOLOGY

## Research Design

This study employed a qualitative exploratory design to examine the impact of transitioning to an ALF from the perspective of family caregivers. Semi-structured interviews using a guide with open-ended interview questions and probes were used to gain an in-depth understanding of the experiences caregivers faced as a result of caregiving, which ultimately led to the transition to an ALF.

## Sampling Methods

Participants were gathered using purposive and snowball sampling. A director of an ALF was contacted who was able to provide the contact information of potential participants interested in this study. Participants from this sample pool were asked if they knew of other individuals who might also be interested in participating. All three of the referrals had agreed to be interviewed. In order to be eligible for inclusion in this study, participants (1) must have been a family caregiver of an older adult and (2) have placed an older adult family member in an ALF or were in the process of considering placement into an ALF. The total sample size for this study was 15 participants.

## Data Collection

All participants were interviewed via phone in English. The average length of the phone interviews was 60 minutes. Participants signed a consent form (Appendix C) distributed via email, with the exception of one, which was mailed directly, allowing permission to be interviewed. All interviews were conducted via phone per request of the respondents using the interview guide (Appendix B). The researcher typed the notes verbatim as the interviews took place, which were later used to transcribe and interpret themes.

## Instrument

An interview guide (Appendix B) was developed by the researcher for the purpose of this study to assist in conducting semi-structured interviews. The interview guide was divided into four sections.

Part one of the four sections consisted of individual circumstances that led to the older adult being placed in an ALF. Example questions included: *What were the circumstances that led to you becoming a caregiver to your family elder?* and *What was your involvement in caregiving prior to your family elder moving to assisted living?* Part two was designed to understand personal attitudes regarding ALFs. Example questions included: *How did you or your family elder make the decision to transition to assisted living*? and *Did family concerns influence your decision?*

Part three of the interview guide aimed at examining personal experiences following the transition. Example questions included: *What was the most difficult aspect of transitioning your family elder to living in an assisted living facility?* and *What can be done to support older adults and their family members transition to an assisted living facility?* Lastly, part four focused on six demographic questions: age, gender, ethnicity/race, employment status, and highest level of education attained.

## Data Analysis Plan

Phone interviews were transcribed verbatim. The data provided by caregivers were analyzed to identify emerging patterns and themes from each of the questions asked in the given sections.

# CHAPTER 4

# RESULTS

This study explored the impact of transitioning to an ALF from the perspective of family caregivers. An interview guide consisting of 15 questions, nine open-ended questions with probes and six items for demographic collection, was used to identify themes in the experiences participants shared. The guide was divided into four parts: (1) experience with caregiving, (2) attitudes regarding ALFs, (3) experience with ALFs, and (4) demographic questions: age, gender, ethnicity/race, employment status, and highest level of education attained.

## Demographics

Of the 15 participants in this study, 12 (80%) were females and three (20%) were males who were caregivers of an older adult. A total of 12 (80%) of the 15 participants ended up placing their loved one in an ALF, and three (20%) were in the process of or were considering placement. Of those surveyed, seven (46.7%) identified as Caucasian, five (33.3%) multiracial, two (13.3%) Latino/Hispanic, and one (6.7%) Vietnamese. The ages of the participants ranged from 28 to 81 years, with a mean age of 57.5 years (*SD* = 15.3). Ten (66.7%) participants were employed, three (20%) were retired, and two (13.3%) were unemployed. In terms of highest level of educational attainment, six (40.0%) had earned either an Associate's degree or higher, five (33.3%) had some college education, and four (26.7%) graduated from high school (see Table 1).

## Becoming a Caregiver

All participants were asked about the experiences and the circumstances that led them to becoming a caregiver. All 15 (100%) of the older adults being cared for by the participants experienced physical or mental health complications that required additional assistance in living and thus led these participants to become caregivers. Nine (60%) of the older adults were diagnosed with Alzheimer's disease and two (13.3%) experienced a major stroke that affected their capacity to function independently. One older adult (6.7%) endured physical health impairments that caused him to fall and injure himself frequently. One older adult (6.7%) experienced a massive heart attack that affected mobility and one (6.7%) had been diagnosed with a severe mental illness and began declining when she started experiencing seizures requiring 24-hour care. Lastly, one older adult (6.7%) was diagnosed with Parkinson's disease (see Table 2).

The examples below are quotes taken from the interview that capture the circumstances leading up to becoming a caregiver, where a common theme was a decline in the older adult's health. One of the AD spousal caregivers shared her experience:

> He was always an independent person. He started getting up at night. I found him urinating in the yard at night, which was very unlike him. He was doing things that were so unlike him and it kept escalating...there was no one else to help.

One of the adult child caregivers shared:

> It became apparent that she could not be by herself. She wasn't eating, or taking her medications, and it became unsafe for her. When I would go over to visit with her, I would find her meds scattered on the floor.

TABLE 1. Demographics (*n* = 15)

| Characteristic | *f* | % | *M* (*SD*) |
|---|---|---|---|
| Gender | | | |
| Female | 12 | 80.0 | |
| Male | 3 | 20.0 | |
| Age (years) | | | 57.5(15.3) |
| 25-39 | 2 | 13.3 | |
| 40-54 | 4 | 26.7 | |
| 55-69 | 5 | 33.3 | |
| 70-84 | 4 | 26.7 | |
| Ethnicity/Race | | | |
| Caucasian | 7 | 46.7 | |
| Multi-racial | 5 | 33.3 | |
| Latino/Hispanic | 2 | 13.3 | |
| Vietnamese | 1 | 6.7 | |
| Employment Status | | | |
| Employed | 10 | 66.7 | |
| Retired | 3 | 20.0 | |
| Not employed | 2 | 13.3 | |
| Marital/Partner Status | | | |
| Married | 9 | 60.0 | |
| Single | 5 | 33.3 | |
| Divorced | 1 | 6.7 | |
| Highest Education Attained | | | |
| High School | 4 | 26.7 | |
| Some College | 5 | 33.3 | |
| Associate’s Degree | 3 | 20.0 | |
| Bachelor’s Degree | 1 | 6.7 | |
| Master’s Degree | 2 | 13.3 | |

Another adult child caregiver reported:

> The day I came to visit my mother, like I always do, I noticed there were 20 unopened bills stuffed under the mattress that hadn't been paid. There were a total of $13,000 worth of unpaid bills. The house insurance bill was due that day at midnight. I dealt with it all that night as I had my child with me…

Another one of the adult child caregivers described her experience:

> Nothing was right…phone messages were on the floor…I was losing my life. I got a divorce because of it. I knew my life was going to change.

## Involvement in Caregiving

Participants were asked about their level of involvement in caring for their older adult. This question was designed to get an understanding as to what tasks were involved in their provision of care, such as grooming, bathing, cooking, and medication management. An underlying theme in this area is that caregivers were directly involved, in varying degrees, in housekeeping and in physically assisting their older adult. Ten (66.7%) of the participants had lived in the same household as the older adult, in which the older adult came to live with their caregiver after experiencing adversities. Caregivers reported various levels of involvement in their caregiving duties that ranged from grocery shopping, to assisting in personal grooming, and everything else in between (see Table 3).

When asked about their duties in everyday living activities, 10 (66.7%) participants reported that they helped in housekeeping and preparing meals for their older adult. Nine (60.0%) participants assisted their older adult in all their transportation needs, where transportation to doctor visits was the highest reported. Nine (60.%) managed their older adult's medication, which involved frequent communication with doctors, picking up medication refills, administering medication and ensuring medications were properly taken (see Table 3).

TABLE 2. Factors that Led Participants to Become Caregivers (*n* = 15)

| Characteristic | *f* | % |
|---|---|---|
| Circumstances Leading to Becoming a Caregiver | | |
| Alzheimer's Disease | 9 | 60.0 |
| Stroke | 2 | 13.3 |
| Frequent Falls/Loss of Balance | 1 | 6.7 |
| Heart Attack | 1 | 6.7 |
| Mental Health | 1 | 6.7 |
| Parkinson 's Disease | 1 | 6.7 |

Six (40.0%) assisted their older adult in toileting and five (33.3%) reported that they assisted with personal grooming. Five (33.3%) participants managed all bills, finances, and other business matters, such as estates and legal affairs. Four (26.7%) reported having done all of the older adult's shopping or taking the older adult to obtain groceries and other needed household items (see Table 3).

## Events Leading to Assisted Living Facility Placement

All participants were asked how the decision to place their older adult in an ALF was reached (see table 4). Of the 12 participants who decided to place their loved one in an ALF, 10 (83.3%) stated that they needed help with meeting the older adult's increasing demands. Seven (58.3%) participants reported safety concerns for both the older adult and themselves. One (8.3%) reported that the reason for placement was due to a decline in his personal health. Another (8.3%) reported that the decision was based on comparing the cost of an ALF and found it more affordable than hiring a caregiver. Of the 15 participants, three (20%) decided not to place in an ALF. Two of the participants made the decision to care of their family elder until they passed away. The third participant would consider an ALF if health changes in either the caregiver or the older adult occurred, or if there were a change in the caregivers living situation.

TABLE 3. Involvement in Caregiving Prior to Assisted Living Placement ($n = 15$)

| Characteristic | *f* | % |
|---|---|---|
| Living Situation of the Older Adult | | |
| Lived with Caregiver | 10 | 66.7 |
| Did Not Live with Caregiver | 5 | 33.3 |
| Involvement in Care | | |
| Housekeeping/Cleaning | 10 | 66.7 |
| Medication Management | 9 | 60.0 |
| Transportation | 9 | 60.0 |
| Toileting | 6 | 40.0 |
| Grooming | 5 | 33.3 |
| Managing Bills/ Legal Matters | 5 | 33.3 |
| Shopping | 4 | 26.7 |

*Note*. More than one response was possible.

Participants shared similar experiences as they related to events that led to the decision to place their loved one in an ALF:

A spouse described caring for her husband on her own:

> It was due to safety reasons. My kids were telling me that it was becoming too dangerous to have him at home. We lived on busy street, and with him not being able to drive, he became a wanderer. He needed to be somewhere where he couldn't roam around, for his own safety and mine.

A spouse explained how caregiving at home was impacting his health:

> It took a while, but I started getting run down. I was losing the ability to take care of her. I had some episodes and went to the hospital. Family members encouraged me to get assistance in caring for her; that caring for her was beginning to affect me and caused me to get ill.

A spouse described the impact of caregiving on her ability to maintain a job:

> I needed more help because I was still working. At times I needed to travel. I would travel and take him with me but that became troublesome. I lost him at the airport when he would go to bathroom. Sometimes he would take so long to go to the bathroom, and sometimes he just wouldn't come out. He began having hallucinations…I thought this was only going to get worse. It became a safety issue. I wasn't sleeping at night. I was hyper vigilant.

An adult child recalled the circumstances that led to the decision to transition her mother:

> It became a safety issue. She was not taking her meds, and she was not eating. She was leaving the house at night. She once flagged down a policeman. She wasn't safe. I couldn't manage it anymore; the 15 calls a day from my mom or from the neighbors that she was out roaming or bothering them. I had a job to keep. My mom was always a difficult person to deal with even before the dementia. She was not a happy person and it became exacerbated. She became combative.

Another adult child provided an idea of what led her to place her father in an ALF:

> The last 6 months, his Alzheimer's became profound. He became angry. He wouldn't know who I was. He would throw me out of my own house. One time, I put him to bed, and I went to check on him and he wasn't there. He had gotten out. It was raining that day and he had fallen in the mud in the front yard. Luckily, I had a gate around my house to keep him in. He didn't know what he was doing. He was angry and when he was angry he became very strong. He said many things to me; awful things, but I didn't care. I knew it was the disease talking. It wasn't him. I felt I couldn't keep him safe anymore.

A spouse recalled what led to the decision to place her husband in an ALF:

> He couldn't do anything on his own anymore; getting dressed, knowing what to do, everything became very difficult. I'll put it this way: there was little he could do on his own. Once he got out of the house and got lost, the whole neighborhood was out looking for him. I even bought him one of those locators.

TABLE 4. Deciding Factors Leading to Assisted Living Placement (*n* = 12)

| Characteristic | *f* | % |
|---|---|---|
| Decision to Place in an ALF | | |
| Yes | 12 | 80.0 |
| No | 3 | 20.0 |
| Events Leading to AL Placement | | |
| Increasing Demands | 10 | 83.3 |
| Safety Concerns | 7 | 58.3 |
| Caregiver Health Complications | 1 | 8.3 |
| Financial Reasons | 1 | 8.3 |

*Note*. More than one response was possible.

## Attitudes Regarding Assisted Living Facilities

The following questions were geared towards understanding caregivers' attitudes regarding ALFs prior to placement, how the decision was finally made, and the process of placement (see Table 5). In regards to attitudes towards placement, four (33.3%) participants experienced feelings of guilt for not being able to continue care at home and for placing the care recipient in an ALF. Three (25%) of the participants had previously placed their loved one in a facility but were unsatisfied with the level of care, causing them to relocate their older adult to a more appropriate facility. Two (16.7%) felt that AL placement was inevitable and something that needed to happen; two others (16.7%) expressed being hesitant about AL placement; two others (16.7%)

In terms of how the decision was finally made, eight (66.7%) found comfort in knowing that the chosen facility was equipped to handle the older adult's condition, whereas many participants reported feeling content with their decision to place their loved one. Five (41.7%) based their decision on knowing that their older adult would be taken care of more adequately than if her or she were to remain at home. Five (41.7%) participants chose a facility because it offered security. Five (41.7%) felt that they had made the decision based on a supportive and caring staff at the facility. One (8.3%) reached the decision to place the older adult due to a decline in his own personal health.

In describing the process of placement, caregivers identified unique experiences, however a common theme was that most participants (8 or 66.7%) described the process as difficult and associated their experience with negative emotions. Seven (58.3%) of the participants did not reveal to their loved one that they were transitioning him or her to an ALF in fear that her or she would resist. Five (41.7%) felt relief after the placement was made. Five (41.7%) participants felt that the transition was their only option and something that had to happen. Four (33.3%) reported to experiencing feelings of guilt as a result of not being able to remain caring for the older adult and for having to place him or her in assisted care.

A spouse described the experience as:

> It was horrible. I always thought I would never commit [place] him. I felt I could [take care of him] at home. I then realized I wasn't equipped for that anymore. I knew I couldn't keep him here anymore. I felt very guilty. I know now he is very well taken care of.

Another spouse described the experience as:

> We left her there to adjust for a few days on her own. That was the hardest thing I've ever done in my life. I came home, went into bed, and sobbed. It was difficult to leave her. I felt guilty that I couldn't continue to care for her. You can't describe it to someone what the experience is like. The only one who can understand is the person who has gone through this. It's such a difficult thing to describe.

An adult child who placed her parent had said:

> I was in crisis mode at that point. I thought I was going to have a nervous breakdown. I was placing my mother in someone else's care. I was afraid my mother would see me in the administrative office [of the facility]. I, of course, did not tell her I was putting her there. She would have fought me. Once there, I also felt relieved. Relieved that they [the neighbors] weren't going to call me all day anymore. She would be somewhere where they knew how to handle someone with dementia.

This next quote was also from an adult child placing her parent:

> I had constant fears. My whole journey was that I was dismantling her life without her knowing I was doing it. I gave myself permission that I was dismantling her life for the purpose of helping her, but I felt like shit, for having to take decisions into my own head.

This quote was from an adult child placing her parent:

> Emotionally, I was going to lose my mother, the only person who would ever do anything for me. I am losing the only parent I've ever known…there was no decision to make. This is what needed to happen.

A caregiver searching for a facility recounted:

> You hear horror stories. There's one by my house and you see the conditions. The conditions are not good. The staff doesn't take care of residents like they should. Residents are just there waiting out their deaths.

This was a quote from a spouse:

> It's been my worst nightmare…I don't wish it on anyone.

Another quote from an adult child placing her parent

> I was losing my life. I was getting a divorce because of it. I knew my life was about to change. I wondered if I would be good enough to take care of her. Now I am worried about what I would do when she is gone.

## The Most Challenging Aspects of an AL Transition

Participants were also asked what the most difficult aspect of transitioning their older adult was (see Table 6). Four (33.3%) participants were concerned that their older adult would not like the facility. For three (25%) of the participants, it was watching their family elder decline physically and mentally. Two (16.7%) participants reported that the most difficult part was in knowing that they were the ones who had placed their older adult in an ALF. Two (16.7%) mentioned that it was the fact that their older adult was not going to get better. Two (16.7%) reported that it was in realizing they could no longer manage the caregiving on their own. Two (16.7%) participants stated that seeing their older adult as a different person due to their disease was the most challenging. One (8.3%) said that having to create a new living space was the most challenging. One (8.3%) mentioned the financial costs of an ALF as an issue. One (8.3%) stated that the most difficult aspect was having to lie to their parent about placing them since they would have refused to go if told he or she was going to an ALF. One (8.3%) reported legalities as the most difficult: this particular participant was sent to court after her mother, who had dementia, reported that she did not want to be in an ALF. One (8.3%) reported that it was most difficult not being able to see their loved one every day. Another (8.3%) reported that not seeing their older adult get the proper care as emotionally straining, (see Table 6).

TABLE 5. Attitudes Regarding Assisted Living Facilities (*n* = 12)

| Characteristic | *f* | % |
|---|---|---|
| Attitudes towards Placement | | |
| Experienced Feelings of Guilt | 4 | 33.3 |
| Had Previously Placed in an ALF | 3 | 25.0 |
| Felt AL Placement Was Inevitable | 2 | 16.7 |
| Hesitant about the Placement | 2 | 16.7 |
| How the Decision Was Finally Made | | |
| Facility Was Equipped to Handle Dementia | 8 | 66.7 |
| Adequate Care Offered by Facility | 5 | 41.7 |
| Secure Facility | 5 | 41.7 |
| Supportive and Caring Staff | 5 | 41.7 |
| Decline in Personal Health | 1 | 8.3 |
| Process of Placement | | |
| Difficult with Negative Emotions | 8 | 66.7 |
| Did Not Tell Older Adult About | 7 | 58.3 |
| Felt Relief Afterward | 5 | 41.7 |
| Felt the Transition Had to Happen | 5 | 41.7 |
| Experienced Feelings of Guilt | 4 | 33.3 |

*Note*. More than one response was possible.

These quotes express what participants felt was the most difficult aspect of transitioning from home to an ALF.

A spouse described the experience as:

> The fact that I was the one that put him there. I felt guilty. I take one day at a time. Some days are worse than others. He is a different person now. He’s not the man I married.

A spouse had stated:

> If you gave me a checklist, I can probably check them all. There were many things that were difficult. It [assisted living] is very costly. I did not have healthcare insurance and I am diving into my personal savings. I had a pretty good savings, but what do you do when the money runs out?

A spouse recalled a particular time she went to visit her husband at his ALF:

> When I went back a week later, I found him in the lobby, sobbing and saying, "I hate this place, I want to go home."

An adult child described the challenges of placing her parent:

> Seeing her not recognize her own things was the hardest part. She would go through her photo albums like crazy. We had to throw half of her stuff out. We had to get rid of her car. We had to trick her [to get her to an ALF].

An adult child discussed the challenges in placing her parent in an ALF:

> Knowing she doesn't have the quality of life I want her to have. It's not something I can improve. It's hard to see her like this. They were asking me if I wanted to take the medications away, and it's just that I know she's not going to get better but I don't want to play God either.

A spouse revealed her greatest challenges:

> It's most difficult accepting that he has something he is not going to get better from and having to deal with the disease.

This quote is from an adult child who placed her parent:

> …leading up to it, signing the contract, packing up her stuff, getting her room ready. We chose to bring her things that were special, her paintings, which was stressful, painful, and difficult because I was creating the space my mom was going to die in. The first day was the hardest. I had to lie. I told her we were going to this place because they were going to be painting her apartment and we couldn't be around the fumes. That was one of the hardest days of my life.

Another participant had stated:

> The disease. The decline. It's different for each person, but you are going to watch your parent die. You forget that what you feel is grief. We are mourning and losing somebody while they are still alive…that was the hardest part for me to accept. I wasn't prepared for that.

## Involvement after Placement

All (12) participants who placed their older adult in an ALF remained involved in the care of the older adult and continued to assume responsibilities in caregiving even after placemen (see Table 7). All 12 participants who chose to place their loved one in an ALF continued to visit them on regular basis. Ten (83.3%) participants who had managed legal, financial, and business matters prior to AL placement, continued to do so following the transition. Ten (83.3%) participants maintained frequent communication with facility staff and care providers to become updated and informed of the older adult's condition, and also advocated for additional services when necessary. Ten (83.3%) participants remained involved in the medical care and in medication management. Two (16.3%) of the participants took the older adult on frequent outings for recreational purposes or to run errands.

An adult child stated:

> It is a fallacy of many that the caregiving stops once you place them in assisted living, but the caregiving never stops. You will always be their caregiver and be the one helping them until their final day.

A spouse had included:

> …know that although the older adult is in an assisted living facility, the role of a primary caregiver will most likely continue for as long as the life of the older adult.

## Caregivers' Perspectives on Types of Support Needed

The next question was in regard to caregivers' perspectives on what they felt could be done to support caregivers in this situation. Eight (53.3%) participants suggested attending support groups and talking to other people who were going through the same experience to help alleviate the unknown regarding the disease of the older

TABLE 6. The Most Difficult Aspect of Transitioning Older Adult to Assisted Living Facilities (*n* = 12)

| Characteristic | *f* | % |
|---|---|---|
| Participant Responses | | |
| Older Adult Not Liking Facility | 4 | 33.3 |
| Decline in Older Adult's Health | 3 | 25.0 |
| Having to Make the Decision | 2 | 16.7 |
| Knowing Older Adult Would Not Get Better | 2 | 16.7 |
| Not Being Able to Continue Caregiving at Home | 2 | 16.7 |
| Seeing Older Adult as a Different Person | 2 | 16.7 |
| Creating New Living Space for Older Adult | 1 | 8.3 |
| Financial Cost | 1 | 8.3 |
| Having to Lie to Older Adult about Placement | 1 | 8.3 |
| Legalities | 1 | 8.3 |
| Not Seeing Older Adult Everyday | 1 | 8.3 |
| Older Adult Not Getting Proper Care | 1 | 8.3 |

*Note*. More than one response was possible.

TABLE 7. Caregiver's Level of Involvement Following Assisted Living Placement (*n* = 12)

| Characteristic | *f* | % |
|---|---|---|
| Participant Responses | | |
| Visitation and Contact | 12 | 100 |
| Assumed Legal/Financial/Business Matters | 10 | 83.3 |
| Communication with Staff /Care Providers | 10 | 83.3 |
| Involved in Medical Care and Medications | 10 | 83.3 |
| Frequent Outings | 2 | 16.3 |

*Note*. More than one response was possible.

adult. Five (33.3%) reported they wished they had more help from other family members to assist in the caregiving and in the decision making process. One (6.7%) reported financial resources to better deal with the financial strain associated with the expenses of caregiving (see Table 8).

A spouse described what was helpful for her as:

> For me, I don't know. I feel helpless. There's nothing I could do. I am thinking of getting a part time job to keep busy. I go outside, pull weeds in my garden, and I have a big dog that keeps me company.

A spouse had offered:

> Support groups were my lifesaver. Getting advice from others going through the same thing. It makes it easier knowing you are not alone.

A spouse suggested the following:

> I had help in that I went to a caregiver support group. The people in my group were very supportive. As a caregiver, you need information, you need support, you need feedback, and it helps to talk to others who have gone through this same experience. You need to educate yourself. The Alzheimer's Association was such an incredible tool. They bring people to educate you; on the prognosis and what is going to happen. They bring lawyers to explain the process, power of attorney, to have it all planned.

An adult child had stated:

> You need others to help you. Looking back, I didn't have the emotional support. I felt alone. Some don't want the help and feel that this brings them a purpose. Some people aren't accepting of having others stepping in to assist. I need to ask for help, either with other family members or with professionals. Caregivers have an overdeveloped sense of responsibilities. I needed more sibling support. I felt very alone. It can get depressing. I wanted to just talk to my husband about it. I wanted someone to listen to me and understand what I was going through. I have a great husband, but I just didn't feel like he knew how I felt. This is the worst disease imaginable.

An adult child had described her thoughts on support needed in the following way:

> I don't know. I think to talk about it, even when my grandfather had it [dementia] no one talked about it. That's how my family was, they didn't talk about it. Any

> noise that can be made. It's not just about the cooking and cleaning. It's more about the emotional impact of it. If more attention can be given to the disease and what's it's like. If there was more awareness, not just about the disease, but more about the heart that it takes to care for someone with the disease. I made a movie about this, that is coming out next month…It's very isolating. It's very lonely. You don't want to go out. You don't want to have anyone over. I didn't care if he had an episode with my friends here, but still. It's abundantly sad, isolating, and lonely. I didn't have a social life. I didn't date. I was single. You tend to forget about taking care of yourself.

An adult child had offered the following:

> Support groups, I can image would be helpful. I never went. I have support with my brother. I think talking to other people is key.

A spouse had stated:

> I dealt with it on my own. Support groups weren't for me and I never went to those.

An adult child reported:

> I know it's very difficult. I found it helpful to go to support groups, granted you have to find the right one. Finding the person to go to. For me, I had a social worker. Having a continual person to form a relationship with and go to for information and resources.

TABLE 8. Caregivers' Perspectives on Types of Support Needed (*n* = 15)

| Characteristic | *f* | % |
|---|---|---|
| Participant Responses | | |
| Support Groups | 8 | 53.3 |
| Assistance from Other Family Members | 5 | 33.3 |
| Emotional Support | 5 | 33.3 |
| Information/Resources | 5 | 33.3 |
| Financial Support | 1 | 6.7 |

*Note*. More than one response was possible.

## Offering Advice to Others Experiencing Similar Situations

When asked what advice they would give to someone who is caring for an older adult and considering alternative care to meet the older adult's growing needs, many participants offered insightful suggestions (see Table 9).

One spousal caregiver had stated:

> Caregiving doesn't stop. It's like caring for a child, but a child eventually learns to care for himself. When you have dementia, you can be violent. There are so many twists and turns. I am a big advocate of support groups. People are different; some will care for people at home and do what they need to do.

Another spouse had suggested:

> Get help. Seek help. Look after yourself. You need to take care of yourself because if you don't, you might go before the older adult.

An adult child had stated:

> I would do whatever it took to get parents to discuss end-of-life decisions no matter how avoidant they may be about the topic. They need to discuss burial, power of attorney, and stuff like that. I would have been more aggressive about that. There's nothing worse than your parent dying and being at the cemetery or mortuary and deciding on what to choose for your dying parent.

An adult child had recommended the following:

> The only thing I could say is don't isolate yourself. Let people who want to be there for you, be there. The anticipation of the move is far worse than the actual move. Don't assume that other people can't care for your loved one. It's really hard to admit that. I didn't want him to go to a facility, but he's better now where he is.

An adult child had stated:

> As hard as it is, let go of the guilt. Stop feeling that you need to be the one caring for the family member. I feel I am still caring for her even though she's in a facility. She's getting the care she needs in there and I am still doing what I need to care for her.

An adult child had offered:

> There is so much you don’t know, and if you don’t know where to go, go look into places. Seek and get help. You need information. Also, don’t take anything personal while you’re caregiving. Put the oxygen mask on yourself. If you can’t begin to see when you’re losing it, you won’t be able to make it to help others. And also remember that everyone is different.

Another adult child had recommended the following:

> Be good to yourself. Be kind to yourself. Take a day and do absolutely nothing and don’t feel guilty about it. Nothing can prepare anybody for what this is, so give yourself a break. Compile a list of things to do and get them checked off; DNR [Do Not Resuscitate form], trusts, will, estate sales, transfer of names, be informed of Medicare D, and of medication changes. Have a list of support groups nearby. The burden will be less. Next thing, I would tell someone [who is experiencing this situation] that you are going to watch your parent die, so prepare yourself for the grief. It becomes consuming. You forget that what you feel is the mourning. We are grieving; we are losing somebody while they are still alive.

TABLE 9. Caregivers’ Advice to Others Facing Similar Situation (*n = 12*)

| Characteristic | *f* | % |
|---|---|---|
| Participant’s Recommendations | | |
| Seek Help/Information/Resources | 6 | 50.0 |
| Join Support Groups | 5 | 41.7 |
| Practice Self-care | 5 | 41.7 |
| Understand Benefits of AL Placement | 5 | 41.7 |
| Caregiving Continues after Placement | 2 | 16.7 |
| Discuss End-of-Life Decisions | 2 | 16.7 |
| Release Feelings of Guilt | 2 | 16.7 |

*Note*. More than one response was possible.

# CHAPTER 5

# DISCUSSION

This study was based on interviews with caregivers from areas within the County of Los Angeles to obtain their experiences when caring for an older adult and then examined how AL placement had an impact on their well-being**.** From a social worker's perspective, the purpose of conducting this study was to identify useful strategies to better assist clients who are caregivers of an older adult. The responses gathered from these participants reinforced some of the findings found in the review of the literature. Of the 15 caregivers interviewed, 12 (80.0%) decided to place the older adult in an ALF.

## Summary of Key Findings

The participants in this study were mostly adult children (46.7%) or spouses (33.3%), with an average age of 57.5 (*SD* = 15.3) years. Two-thirds of the caregivers were living with the older adult prior to the placement in an ALF. The primary reasons for placing a loved one in an ALF were declining health and risks to safety. Over three-fourths of the participants decided on ALF placement due to declining health of the older adult and over half reported that the transition was due to safety concerns. Participants had reported that the needs of the older adult intensified as their health conditions progressed, which also ended up compromising their safety. These findings are consistent with research by Kim et al. (2011), which found that ALF placement was highly contingent upon the functional decline due to the loss of health by the older adult.

Kelsey et al. (2010) also reported that caregivers who placed their older adult in an ALF did so as a result of both declining health in the older adult and for safety concerns.

Prior to ALF placements, caregivers in this study assumed various caregiving tasks, which ranged depending on the older adult's individual abilities and disabilities. These tasks included assistance in grooming, toileting, bathing, housekeeping, cooking, medication management, shopping, transportation, and managing legal and financial matters. All caregivers reported that they sustained frequent visits and most continued to manage financial and legal matters, and maintained frequent contact with facility staff to discuss the older adult's well-being and to advocate for additional services as needed. During one of the interviews, a participant provided her conception of caregiving following AL placement by stating: "it is a fallacy of many that the caregiving stops once you place them in assisted living, but the caregiving never stops. You will always be their caregiver and be the one helping them until their final day." Corresponding with this previous statement, another participant expressed: "know that although the older adult is in an ALF, the role of a primary caregiver will most likely continue for as long as the life of the older adult." These findings are consistent with those found in the research by Kemp (2008), where it was reported that caregivers continued to provide support to family members even after placement in an ALF.

Despite the demands of caregiving, participants spoke more about the psychological impact of having to make important decisions for the older adult that ultimately affected his or her life. Two participants spoke of the importance of having end-of-life discussions with their older adult to become prepared for final arrangements. These matters, which include the implementation of a will, an assigned power-of-attorney, advanced directives, quality of life towards the end-of-life, and burial planning were discussed and planned out beforehand in two of these cases. Those participants who had done so considered themselves better prepared in their capacity as a primary caregiver.

When asked about what was helpful, or could have been useful at the time, three-fourths of the caregivers reported the benefits of support groups and the need for more support for caregivers. Participants shared a common theme of not attending to personal needs and the need to encourage family caregivers to do so. This finding supports the results of a study conducted by Robinson et al. (2012) who asserted, that caregivers need to be educated on the importance of self-care, otherwise placement in an ALF is much more likely. One caregiver offered a suggestion in the form of advice that heightens this notion by stating "put the oxygen mask on yourself first and foremost" when caring for an older individual.

## Study Limitations

The limitations of this study primarily center on its low internal and external validity. The lack of the use of an experimental design means that causal inferences cannot be made from any of the results generated from this study. These findings cannot be generalized to the entire population of family members of older adults who have transitioned to an ALF, primarily due to this study's small sample size that did not represent diverse populations and cultures. The geographic area was also limited. These findings may not apply, for instance, to all areas of the United States, because not all states have equal accessibility to an ALF as a result of uneven ALF distribution on a national level (Stevenson & Grobowski, 2010). In addition, these findings pertain to those relocations that have occurred from independent living to assisted care placements, and thus, cannot be generalized to other housing options such as hospice care, nursing homes, senior living communities, and community care retirement communities.

Although careful thought was put into question formulation based on the review of the literature, there is a high degree of subjectivity associated with qualitative research. There is no guarantee that the questions will cover the full range of possibilities for a given concept or variable. The results of this study were subject to the interpretation of the researcher and may not have been perceived as intended by the participants. Moreover, because the interviews were conducted via telephone there was a disadvantage in the reduction of social cues.

## Implications for Further Research and Practice

The implications for future research indicate the importance of more studies on effective interventions for caregivers. Participants in this study discussed the need for more information on long-term care and caregiving. Caregivers initially did not know where to go for answers, and wanted to become informed on many aspects, including their older adult's illness and what to expect of their progressing disease. Caregivers wanted to know where to go for resources and to whom to talk to. While support groups were reported to be very beneficial by caregivers, more research is needed to determine what types of support groups are helpful to caregivers. The implications for future research include studies on the need for more research on the needs of family caregivers who are considering placement and how to support families once they have decided to place an older adult in an ALF.

The number of people moving into ALFs will continue to increase as more baby boomers enter older adulthood. In order to develop relevant interventions in this field, social workers need to become more aware of how older adults and their family members cope with the transition to ALF environments. Social workers play a critical role in health care settings by ensuring that older adults and their family members become knowledgeable about long-term care options and resources.

This study suggests that more interventions are needed for family members and older adults to prepare them for the ALF transition. For social workers who work in ALFs, post transition support in the form of orientation meetings for family members and older adults on what to expect during the transition process would likely be helpful. The inclusion of family members in activities at ALFs would likely promote ongoing closeness between the older adults and their family members. Lastly, offering support groups for residents and for family members would also likely improve the scope and quality of care provided in ALFs.

# APPENDICES

# APPENDIX A

# RESEARCH STUDY FLYER

*The Impact of Transitioning to an Assisted Living Facility from the Perspective of Family Caregivers*

You are invited to participate in a study by Melissa Alamilla, a thesis student, in the Master's of Social Work program at California State University, Long Beach.

The purpose of this research study is to explore your experience as a family caregiver of an older adult who has transitioned to an Assisted Living Facility or is in the process of planning for a transition.

A one-on-one interview, lasting approximately 1 hour, will be conducted to understand your personal experience as a caregiver. Your participation or non-participation is voluntary and will remain confidential. Your participation may provide social workers with useful information to better understand the needs of family caregivers of older adults who are making the transition to an Assisted Living Facility.

To participate in the study, you must be a family caretaker of a family elder providing care without financial gain and be over the age of 18.

If you would like to participate, you can contact me at XXX-XXX-XXXX and we can set up a time to conduct the interview.

Thank you for your consideration!

# APPENDIX B

# QUESTIONNAIRE INTERVIEW GUIDE

## Interview Guide

I. *First, I would like to begin the interview by collecting some background information about your experience as a caregiver prior your family member moving to an Assisted Living Facility. You may take as much time as needed.*

What were the circumstances that led to you becoming a caregiver to your family elder?
Probes:

- Health set back of the elder?
- Always been the person in the family to take on the caregiver role?

What was your involvement in caregiving prior to your family elder moving to Assisted Living?
Probes:

- Did family elder live with you?
- Were you involved in personal care (e.g., bathing, grooming) of family elder?

What led to the decision to transition your family elder to an Assisted Living Facility?
Probes:

- Decline in your health?
- Decline in family elder's health?

II. *Next, I would like to ask you are about your attitudes regarding assisted living prior to transitioning your family member to an Assisted Living Facility:*

1. How did you or your family elder make the decision to transition to assisted living?

Probes:

- Describe the process you went through.
- What were your fears or concerns?
- How did your family elder and/or you finally come to decide that it was the right decision?

2. Did family concerns influence your decision? Please explain.

III. *The next set of questions ask you about your experience with Assisted Living after your family elder moved into the facility.*

3. What was the most difficult aspect of transitioning your family elder to living in an Assisted Living Facility?

Probes:

- Loss of independence of family elder?
- Roommate problems?
- Financial drain?

4. What can be done to support older adults and their family members transition to an Assisted Living Facility?

Probes:

- Orientation meeting for family members and the family elder?
- Educational workshops on preparing for Assisted Living?
- More family events at the Assisted Living Facility?

5. What advice would you give to someone who is caring for an older adult and considering alternative care to meet their growing needs?

6. Is there anything else you would like to tell me about you or your family elder's experience with transitioning to an Assisted Living Facility?

Lastly, I would like to gather basic demographic information from you:

A. What is your age:
B. Gender:
C. What ethnic group do you identify with?
D. What is your employment status?
E. What is your marital/partner status?
F. What is the highest level of education you have attained?

This concludes the questions that I had for you. Is there anything you would like to add or do you have any questions?

Thank you for your participation!

# APPENDIX C

# CONSENT FORM

## CONSENT TO PARTICIPATE IN RESEARCH

### *The Impact of Transitioning to an Assisted Living Facility from the Perspective of Family Caregivers*

You are asked to participate in a research study conducted by Melissa Alamilla, an MSW student in the Master's of Social Work Program at California State University, Long Beach**.** You were selected as a possible participant in this study because you are a family caregiver providing care to an older adult and have considered assisted living placement as an alternative, and are at least 18 years of age.

**PURPOSE OF THE STUDY**
The purpose of this study is to examine the impact of transitioning to an assisted living facility from a caregiver's perspective.

**PROCEDURES**
By volunteering to participate in this study, you will be asked to partake in one recorded interview lasting approximately one hour. If you choose not to be audio taped, the researcher will take handwritten notes. The researcher will meet with you in a public setting chosen by you, or conduct the interview via telephone.

**POTENTIAL RISKS AND DISCOMFORTS**
You may experience mild anxiety or discomfort related to the personal nature of questions regarding your experiences as a caregiver. If you are uncomfortable with the interview questions, you have the right to withdraw from the study at any time. Additionally, a potential risk includes a possible breach of confidentiality.

**POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY**
Although you are not expected to benefit directly by your participation, it is hoped that the results will help social workers gain a better understanding of the needs of caregivers.

**PAYMENT FOR PARTICIPATION**
There will be no payment for participating in this study.

**CONFIDENTIALITY**
Any information that is obtained in connection with this study will remain confidential and will be disclosed only with your permission or as required by law. Even when the study results are reported, your name will not be revealed.
Consent forms will be kept separate from data at all times. Audio taped will be destroyed immediately after they are transcribed and analyzed. The researcher will keep consent forms, transcripts, and handwritten notes for three years from the date the study is completed and then they will be destroyed.
Participants will not be allowed to review, edit, or erase the tape. The researcher and her thesis advisor will be the only individuals who will have access to the data collection materials.

## PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. Participation or non-participation will not affect your benefits or any other personal consideration or right you usually expect. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which in the opinion of the researcher warrant doing so.

## IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact me XXX-XXX-XXXX, or my thesis advisor Molly Ranney at 562-985-4684.

## RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact the Office of University Research, CSU Long Beach, 1250 Bellflower Blvd., Long Beach, CA 90840; Telephone: (562) 985-5314 or email to research@csulb.edu.

## SIGNATURE OF RESEARCH SUBJECT (AND) OR LEGAL REPRESENTATIVE

I understand the procedures and conditions of my participation described above. My questions have been answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form.

__________________________________________
Name of Subject

__________________________________________ _______________
Signature of Subject Date

Consent for Audio-taping:

__________________________________________ _______________
Signature of Subject Date

# APPENDIX D

# ORAL SCREENING SCRIPTS

# ORAL SCRIPT FOR THOSE I APPROACH IN MY SOCIAL CIRCLE

Hello. My name is Melissa Alamilla and I am a student in the Master's of Social Work Program at California State University, Long Beach. As part of the Master's program, I am writing a qualitative thesis, entitled "*The Impact of Transitioning to an Assisted Living Facility from the Perspective of Family Caregivers*." I am interviewing family caregivers of family elders, who are 18 years of age or older. The primary purpose of conducting this research is to explore the implications involved in the provision of care to an older adult and the perceptions caregivers have regarding the transition to assisted living. Are you interested in participating?

**If they say yes:**

Thank you so much for deciding to participate in this study.

**If they say no:**

Thank you very much for taking the time to listen to me. Have a great day.

# APPENDIX E

# ORAL SCRIPT FOR BEGINNING CONTACT TO THOSE WHO RESPOND TO RESEARCH FLYER

# ORAL SCRIPT FOR BEGINNING CONTACT TO THOSE WHO RESPOND TO RESEARCH FLYER

Hello. Thank you for responding to my flyer. My name is Melissa Alamilla and I am a student in the Master's of Social Work Program at California State University of Long Beach. As part of the Master's program, I am writing a qualitative thesis, entitled: "*Examining the Impact of Transitioning to an Assisted Living Facility from a Caretaker's Perspectives*." I am interviewing caregivers of family elders, who are 18 years of age or older, who provide care without monetary compensation. The primary purpose of conducting this research is to explore the implications involved in the provision of care to an older adult and the perceptions caretakers have regarding the transition to assisted living. Are you interested in participating?

**If they say yes:**

Thank you so much deciding to participate in this study. Let's talk about when and where an interview might be convenient for you.

**If they say no:**

Thank you very much for taking the time to call me. Have a great day.

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# REFERENCES

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