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# Decision-Making Processes of Primary Informal Caregivers Regarding Care Recipients' Moves to Memory Care

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DECISION-MAKING PROCESSES OF PRIMARY INFORMAL CAREGIVERS  
REGARDING CARE RECIPIENTS' MOVES TO MEMORY CARE

by

VICKI JOY STANLEY

Under the Direction of Mary M. Ball

ABSTRACT

Most persons with a dementia are cared for in the home by family members who experience a broad and considerable amount of stress and whose caregiving careers may include planning for or initiating moves to memory care units (MCUs). This study examines the decision-making processes of primary informal caregivers regarding their care recipients' moves to MCUs. Grounded theory methods were used to collect and analyze data in two long-term care (LTC) facilities varying characteristics including capacity, state licensure, costs and resident profiles. Specific aims are two-fold: 1) advance an understanding of how primary informal caregivers of persons with a dementia made decisions for formal memory care, and 2) identify the important factors related to the decision-making process.

INDEX WORDS: Aging, Alzheimer's disease, Caregiver, Care recipient, Cognitive, Decisions, Dementia, Grounded theory, Memory care

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REGARDING CARE RECIPIENTS' MOVES TO MEMORY CARE

by

VICKI JOY STANLEY

A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of

Master of Arts

in the College of Arts and Sciences

Georgia State University

2011

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REGARDING CARE RECIPIENTS' MOVES TO MEMORY CARE

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August 2011

In loving appreciation of  
Richard  
for his unconditional support,  
endless enthusiasm,  
and unquestionable ability to embrace my goals;  
and  
in loving memory of  
June and Charles  
whose lives continue to provide inspiration.

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## CHAPTER 1

### Introduction

#### *Statement of the Problem*

More Americans are living longer (Alzheimer's Association, 2010b, March; Vincent & Velkoff, 2010, May). The U. S. Census Bureau (2010, February) projects that between 2008 and 2050, the population aged 65 and older will grow from approximately 38.7 million Americans to roughly 88.5 million. By 2050, older Americans are expected to encompass a full 20 percent of the general population (Vincent & Velkoff, 2010, May). Growth of the older population is fueled in part by the large cohort of aging baby boom members, those born between the years 1946 and 1964 (Alzheimer's Association, 2010a, March). Medical advances and socio economic improvements since the births of baby boomers contribute to increased longevity (Alzheimer's Association, 2010b, March; Johnson, Toohey, & Wiener, 2007; Plassman, et al., 2007; Suh & Shah, 2001). Longevity, however, is a risk factor for developing a dementia (Alzheimer's Association, 2010b, March; Johnson, et al., 2007; Plassman, et al., 2007; Suh & Shah, 2001). Over the general course of a lifetime, individuals may be expected to accrue co-morbidities and chronic disabilities. Coupled with the onset of a dementia, a greater number of aging adults will require increasing numbers of caregivers and care options creating a complex matrix of problems and problem-solving for multiple needs (Johnson, et al., 2007; Alzheimer's Association, 2010c, May). While these factors are staggering on their own, it is important to delve deeper and take a closer look at the substantial changes American society is facing in issues related to dementia.

Most persons with a dementia are cared for by family members, known as informal or "unpaid" caregivers (Alzheimer's Association, 2010b, March, p. 23). In the year 2009, the Alzheimer's Association stated that nearly 11 million informal caregivers (family and/or friends)

provided care for a person or persons with a dementia (2010b, March). Among those with a dementia, most of whom have AD, approximately 70 percent are cared for in the home (Alzheimer's Association, 2010b, March).

During their caregiving careers, family caregivers of persons with a dementia experience considerable stress and adverse effects associated with stress (Alzheimer's Association, 2010a, March; Alzheimer's Association, 2010b, March; Alzheimer's Association, 2010c, May; Gwyther, 1998; McCallion, Toseland, Gerber, & Banks, 2004). Stressors may include strained family relations and financial burden, as well as emotional and physical tolls that affect caregivers' quality of life and general well-being (Alzheimer's Association, 2010a, March; Alzheimer's Association, 2010b, March; Alzheimer's Association, 2010c, May; Armstrong, 2000; Gwyther, 1998; Houser & Gibson, 2008; McCallion, et al, 2004.; Rhee, Degenholtz, Lo Sasso, & Emanuel, 2009; Spitznagle, Tremont, Davis, & Foster, 2006).

Decision-making related to the care of persons with dementia is especially stressful and may include planning for or initiating moves to memory care units (MCUs) or other institutional settings (Armstrong, 2000; Kelsey, Laditka, & Laditka, 2010; Spitznagle, et al., 2006; Yaffe, et al., 2002). Although a substantial literature examines the decision-making processes surrounding placing a relative with dementia into a nursing home, less research focuses on making a move into a separate secured MCU (Kelsey, et al., 2010; Yaffe, et al., 2002). This research will make an important contribution to the currently limited literature and inform policy and practice.

### ***Research Aims***

The goals of the project were two-fold: (1) Explore the decision-making processes of primary informal caregivers regarding their care recipients' moves into MCUs in LTC facilities by learning who was involved in this process and their various viewpoints, when they made

decisions for memory care during the caregiving career, what locations they considered for memory care, and why they were making decisions for memory care as a LTC option; and (2) Identify the individual-, facility-, and community-level factors that influence those processes, including what individual factors of socio-demographics, health characteristics, and living situations of both caregiver and recipient influenced decision-making, who the network support members were and what network support factors influenced decision-making, what facility-level factors, such as fees, size, location, and staffing influenced decision-making, and what community-level factors, including regulations, reimbursement policies, and availability influenced decision-making.

## **Literature Review**

### ***Background and Significance***

The topic of dementia is broad, but relevant to numerous current changes in American society, including population demographics, personal financial, medical, and emotional health, and societal and economic costs of caregiving. The term dementia itself is a general expression for a number of individual neurological disorders in which cognitive change or decline is chief. Alzheimer's disease is the most commonly occurring of the dementias, but a discussion of AD alone would neglect to present a more accurate effect of dementia on American lives and society. Therefore, an overview of the different types of dementia is included to provide background and context for the present study as well as to assist in illustrating the impact of dementia on the larger societal matters discussed. Though this overview is by no means exhaustive, it helps convey the complexity of issues that caregivers face when challenged to care for and make decisions, such as for moves to memory care, for family members with any dementia.

### ***Impact of Longevity on Rising Rates of Dementia***

An unprecedented aging of the U. S. population is taking place due to the sizeable number of baby boom members reaching their 65<sup>th</sup> birthdays between the years 2010 and 2030 (Administration on Aging [AoA], 2009, Alzheimer's Association, 2010a, March). At the same time, and just as important, the growth rate of the 85 and older population is increasing at an even faster pace (Vincent & Velkoff, 2010, May). According to a U. S. Census Bureau report, this subset of older Americans, the oldest old, is projected to more than triple in number between the years 2010 and 2050, from approximately 5.7 million to more than 19 million (Vincent & Velkoff, 2010, May). At this rate, by the year 2050, those aged 85 and older will account for 35.5 percent of all Americans age 65 and older (Alzheimer's Association, 2010b, March). The

significance of these figures is more fully appreciated when coupled with rates of dementia and interrelated factors.

According to the Alzheimer's Association, (2010b, March), approximately 5.1 million people aged 65 or older are currently living with AD in the United States, accounting for an incidence rate of roughly "one in eight people" (p. 10). Extrapolating from available data they estimate that of these, approximately 2.4 million individuals aged "85-years-and-older" currently have AD (Hebert, Scherr, Bienias, Bennett, & Evans, 2003, as cited in Alzheimer's Association, March, 2010b, p. 14). An additional 500,000 persons under the age of 65 are estimated to already have one form or another of dementia, with nearly 200,000 of these persons estimated as having younger-onset AD, a form that occurs prior to the age of 65 (Alzheimer's Association, 2010b, March). By the year 2050, an approximate total of 13.5 million persons at age 65 or above (16 percent of the age 65 and older population at that time) are anticipated to have developed AD (Alzheimer's Association, 2010b, March). Of those, "an estimated 3.5 million people aged 85 and older will have Alzheimer's (Hebert, et al., 2003, as cited in Alzheimer's Association, 2010b, March, p. 14).

These figures may be considered modest, however, because current estimates utilized by the Alzheimer's Association calculating the approximate numbers of those with AD or some other form of dementia are based upon a limited definition of those conditions (Alzheimer's Association, 2010a, March). According to the Alzheimer's Association (2010a, March), their figures rely upon a definition framed in the Framingham Study limiting dementias, including AD, solely to those documented as being in the "moderate to severe" range (p. 12). The Framingham Study's definition and statistics do not account for persons in the very earliest or

mildest stages of dementia or AD, and therefore project a lower number of individuals that are affected (Alzheimer's Association, 2010a, March).

Several forms of dementia are known to exist, all of which appear to strike with dissimilar frequency (Mendez & Cummings, 2003; Plassman, et al., 2007). Among all types of dementia, however, AD is considered to be the most common and presents a particularly grave health crisis (Alzheimer's Association, 2010b, March; Mendez & Cummings, 2003; Plassman, et al., 2007). A 2010 report states that currently AD is the "seventh leading cause of all deaths in the United States" (Alzheimer's Association, 2010a, March, p. 158). For those who are 65 and older the assertion is more striking (Alzheimer's Association, 2010a, March). Not only is AD the fifth leading cause of death for Americans aged 65 and older (Minino, Xu, Kochanek, Tejada-Vera, 2009), but deaths from AD are mounting when at the same time deaths from other leading causes are decreasing (Alzheimer's Association, 2010a, March, p. 158).

Viewed from another perspective, figures related to AD predict both a broad range of care needs as well as an escalating necessity for more intense care over time (Alzheimer's Association, 2010b). Those with AD are experiencing the disease in different phases dictating multiple intensities of care needs (Alzheimer's Association, 2010b). For the year 2010, those in the earlier or milder phase roughly numbered 28 percent of all those with AD; while approximately 31 percent were found to be in the middle phase; and nearly 41 percent of individuals were experiencing the most acute phase of AD (Alzheimer's Association, 2010b, March). As the cohort of baby boomers advance in age between the years 2010 and 2050 these figures are expected to change (Alzheimer's Association, 2010a, March). By the year 2050, about 23 percent of individuals with AD are expected to be in the milder phase of AD, while nearly 29 percent are anticipated to be in the middle phase, but upwards of 48 percent will be

experiencing AD's most acute phase requiring the most comprehensive and perhaps most intense form of care (Alzheimer's Association, 2010b, March). AD is a disease that develops gradually and imperceptibly, running a course of between 2 and 20 years, causing the potential growth of AD's impact among all dementias within families and society to be astounding (Mendez & Cummings, 2003). Understanding AD's prevalence within a broad set of dementias, therefore, is valuable for grasping the implications correlated with the future needs of older Americans who develop a dementia.

### *Prevalence of Types of Dementia*

Mendez and Cummings (2003) state that among those developing a dementia AD occurs as a single diagnosis approximately 35 percent of the time. At the same time, they note that an additional 15 percent of individuals develop Alzheimer's in conjunction with the second most commonly occurring type of dementia, vascular dementia (Mendez & Cummings, 2003). More recent findings from the Aging, Demographics, and Memory Study (ADAMS) sample taken from the larger Health and Retirement Study (HRS), determined the prevalence of AD to be higher (Plassman, et al., 2007). Their findings concluded that "AD accounted for approximately 69.9 percent of all dementias, while vascular dementia (VaD) accounted for 17.4 percent" (Plassman, et al., 2007). The Alzheimer's Association (2011) relying in part upon the ADAMS sample and data from the Framingham Study, states that AD accounts for approximately "60 to 80 percent of cases" of dementia (p. 5). They agree with earlier findings that VaD occurs second most often, and mixed dementias are now believed to be "more common than previously thought," consisting typically of AD and "most commonly VaD, but also other types, such as dementia with Lewy bodies" (Alzheimer's Association, 2011, p. 5).

One recent study provides an emerging perspective for understanding the prevalence of AD and VaD (Viswanathan, Rocca, & Tzourio, 2009). Viswanathan and colleagues (2009) suggest that the relationship between AD and VaD may be less of two distinct disease processes co-occurring than that of one disease range encompassing both AD and VaD in which an overlap between the two occurs at midrange.

The relative prevalence of other types of dementia follows, providing some perspective of how often they may be found in the general population. Dementia with Lewy bodies (DLB), also referred to as Lewy Body Dementia, occurs in about 15 percent of instances, while VaD without AD develops about 10 percent of the time (Mendez & Cummings, 2003). A group of dementias related to “degeneration of the frontal lobes” is found in about 5 percent of cases of dementia and includes frontotemporal dementia (FTD), a type of dementia that occurs more often just prior to the age of 60 (Mendez & Cummings, 2003, p. 179). A group of other lesser-occurring types of dementia, a few of which are potentially correctable, account for approximately 20 percent or less of cases (Mendez & Cummings, 2003). These include normal pressure hydrocephalus, resulting from blocked “cerebrospinal fluid” flow and Wernicke-Korsakoff syndrome, resulting from a “severe thiamine (vitamin B1) deficiency” related to alcoholism, as well as other types of “toxic-metabolic”, “psychiatric”, “infectious”, and “moving disorder” dementias (Mendez & Cummings, 2003, pp. 8,421, 423).

A relatively new concept regarding the prevalence of dementias is gaining more attention among researchers (Alzheimer’s Association, 2010a, March). Schneider and colleagues (as cited in Alzheimer’s Association, 2010a, March) find indications that mixed types of dementia are common among “most older community-dwelling people,” blurring the line of demarcation between distinctly different dementia diagnoses (Alzheimer’s Association, 2010a, March, p.

164). In an investigation utilizing samples from 3,303 persons with a dementia using data from nine BrainNet Europe study locations in Europe and the United Kingdom, Kovacs and associates (2008) found evidence that among those with AD, and some other dementias, 53.3 percent of persons also had a co-occurring type of dementia (Kovacs, et al., 2008). In 89.6 percent of AD cases alone, mixed dementia was indicated (Kovacs, et al., 2008). The growing awareness of instances of mixed dementia is significant for two reasons. One, it is significant for understanding the difficulties in discovering and applying treatments, cures, and preventative measures within the general population. Two, it is important for appreciating the complexity of caring for persons with a dementia either as a lay person or a professional. Coupling this overview with a brief description of dementia and similar disorders is beneficial for more fully comprehending dementia's impact not only within society, but upon the family and those individuals who receive a dementia diagnosis.

### *Distinguishing Between Three Cognitive Disorders*

#### *Dementia*

Generally noted as “a health care problem of epidemic proportions” (Mendez & Cummings, 2003, p. 2), dementia is the broad term generally used to describe the wide group of “acquired, persistent” (Mendez & Cummings, 2003, p. 4) and “neurodegenerative” (U. S. Department of Health and Human Services: National Institute of Aging/National Institutes of Health [NIA/NIH], 2008, September, p. 42) conditions previously discussed, typically affecting many areas, including memory, decision-making skills, behaviors, speech and language, and mental and physical abilities of individuals. Ellison (2008) notes that “dementia sets in motion profound life changes that affect self-esteem, autonomy, interpersonal relationships,

employment, income, medical care, residential decisions, and plans for the future (pp. 1568-1569).

Various forms of dementia have distinct patterns which may be discerned clinically and through medical examinations, yet a differential diagnosis may not always be easily attained as different forms of dementia can coincide, such as with mixed dementia (Alzheimer's Association, 2010b, March; Jellinger, 2007; Mendez & Cummings, 2003). The presence of unrelated illnesses and conditions, some of which may be previously undiagnosed, or problems resulting from medications or other substances can further confound the identification of a dementia (Alzheimer's Association, 2010b, March; Mendez & Cummings, 2003). However, obtaining a correct dementia diagnosis is important as treatments, including medications, differ enough between some types of dementia that an incorrect treatment plan can cause or increase difficulties for the patient that may be quite serious in some instances (Mendez & Cummings, 2003).

A dementia diagnosis is currently a process that includes a "complete diagnostic work-up" consisting of several types of examinations including physical, mental, neurological, blood and urine labs, imaging, and social history, often with the help of an informant (Mendez & Cummings, 2003, p. 41). This path of diagnosis generally functions to rule out the existence of other diseases and conditions responsible for the symptoms (Mendez & Cummings, 2003). Advances in diagnostics are being made of late, however. Those particularly related to AD are discussed in a forthcoming section. Distinctly different from dementia, yet often confused with it is the condition known as delirium (Mendez & Cummings, 2003).

### ***Delirium***

Unlike dementia, delirium is a temporary disorder of sudden onset (Mendez & Cummings, 2003). The development of delirium causes a noticeably diminished capacity for focusing and maintaining attentive concentration and can include instances of hallucinations and confusion (Mendez & Cummings, 2003). Older adults, particularly those who are hospital patients, are especially susceptible to experiencing delirium (Mendez & Cummings, 2003). It can be caused by ingesting or inhaling toxic substances, experiencing a serious illness, condition, or disease or an infection in the brain, or because of a medication reaction or toxicity (Mendez & Cummings, 2003). Though more often occurring in older adults, neither delirium nor dementia is considered part of the normal aging process (Mendez & Cummings, 2003). A diagnosis is achieved through clinical examinations including patient “history”, blood and cerebrospinal fluids, and less frequently, “neuroimaging” (Mendez & Cummings, 2003, p. 49). Another condition often closely associated with dementia is MCI.

### ***Mild Cognitive Impairment***

Though generally discussed in conjunction with dementia, and with AD in particular, mild cognitive impairment (MCI) is distinctly different (Mendez & Cummings, 2003). Mendez and Cummings (2003) state that MCI is not the same as age-associated memory impairment, i.e., normal aging, nor is it cognitively debilitating in all of the same ways as AD. Among a number of memory complaints older adults may experience, MCI is described as a specific “syndrome” in which “activities of daily living” may remain fundamentally unaffected in a lifestyle of “minimal functional impairment” (Ellison, 2008, p. 1568,1569). Persons with MCI may be found to score outside the normal cognitive range, yet may continue functioning relatively normally in their daily lives (Mendez and Cummings, 2003; Torpy, Lynn, & Glass, 2009).

Ellison (2008), however, suggests that because subtypes of MCI appear to exist with clinically different attributes, different levels of impairment impact otherwise normal abilities. He suggests that persons with MCI must eventually confront “issues of driving, employment, finances, long-term residential planning, and decision-making autonomy” (Ellison, 2008, p. 1571).

Following avenues of research exploring the possibility that MCI could be a very early and detectable phase of AD (Mendez & Cummings, 2003; Mitchell & Shiri-Feshki, 2009; Torpy, et al., 2009), on April 19, 2011, the National Institutes of Health and the Alzheimer’s Association announced the release of new “clinical diagnostic criteria for AD” that included information specifically addressing MCI (U. S. Department of Health and Human Services, 2011, p. 1). The new criteria state that MCI is distinct stage of AD, the second of three stages, following a preclinical stage of ten to twenty years, in which individuals “may or may not progress to Alzheimer’s dementia” (U. S. Department of Health and Human Services, 2011; Jack, et al., 2011). Prior to the announcement, MCI was already linked with a higher risk of developing a dementia, as just over a tenth of those with MCI have been found to later develop dementia (Ellison, 2008).

In a meta-analysis of 41 studies, Mitchell and Shiri-Feshki (2009) found varying degrees of MCI to AD conversion leading them to support the view that MCI is not a “unified disease but [a] heterogeneous disorder with subtypes yet to be fully defined” (p. 263). Among the studies in the meta-analysis indications were found that some individuals diagnosed with MCI improve, some cognitively decline, while others remain relatively unchanged (Mitchell & Shiri-Feshki, 2009). Overall, however, fewer than 50 percent of those with MCI were found to develop a dementia (Mitchell & Shiri-Feshki, 2009). This supports findings stated by Mendez and

Cummings (2003), who note that the range of conversion from MCI to AD is approximately 4 to 36 percent per year with the averages of about 12 to 17 percent, as well as Ellison's (2008) findings noted earlier.

Diagnosis of MCI, according to newly released diagnostic guidelines, is made primarily in the clinical setting following complaints of cognitive changes with "impairment in one or more cognitive domains," while retaining "functional abilities" without the presence "social or occupational functioning" (Albert, et al., 2011, pp. 271, 272). Areas of cognitive impairment may include, in addition to memory problems, difficulties with decision-making and "reasoning", use of language, "visuospatial skills, and attentional control" (Albert, 2011, p. 272).

### *Alzheimer's Disease*

#### *Description of the Disorder*

First described by German physician Alois Alzheimer in 1906, AD is characterized by two distinct microscopic features found in abundance in affected brains, beta-amyloid protein plaques and neurofibrillary tangles of the protein tau (U. S. Department of Health and Human Services: NIA/NIH, 2008, September). In AD, beta-amyloid plaques are believed to disrupt and prevent vital communication between the brain's neurons causing them to die while tau protein tangles have been found to destroy neurons from within (U. S. Department of Health and Human Services: NIA/NIH, 2008, September). In slow progression, neuronal cell death leads to growing areas of brain atrophy, eventually contributing to shrinkage of the brain's general mass and enlargement of its naturally-occurring fluid-filled spaces, the ventricles (U. S. Department of Health and Human Services: NIA/NIH, 2008, September). At this same time, internal changes gradually produce cognitive dysfunction manifesting in a wide array of changes perceived by others and sometimes by the person with AD (U. S. Department of Health and Human Services:

NIA/NIH, 2008, September). These changes include a continuing and escalating “loss of abilities” and shifts away from previously normal behaviors (Krull, 2005).

Because many forms of dementia share similar characteristics, such as loss of memory and decision-making skills, and changes in language use among others, it is tempting to assume that AD, as well as other dementias, follows an exact disease course (U. S. Department of Health and Human Services: NIA/NIH, 2008, September). In reality, however, each experience of AD is individual (U. S. Department of Health and Human Services: NIA/NIH, 2008, September). Age of onset and duration vary as do the number and severity of the problems experienced (U. S. Department of Health and Human Services: NIA/NIH, 2008, September). What is comparable among persons with AD is a disease progression through similar, but broad “stages” beginning in a “preclinical” and undetectable period that may last up to two decades to a neurological decline leading to death (U. S. Department of Health and Human Services: NIA/NIH, 2008, September, pp. 28-29). Throughout, persons with AD gradually lose numerous abilities, including those that are life-sustaining, eventually leaving them completely dependent upon others for their health, safety, and well-being (U. S. Department of Health and Human Services: NIA/NIH, 2009b, May).

### ***Diagnosis of Alzheimer’s Disease***

Diagnosis of AD begins with clinical examinations for dementia, necessary for ruling out the presence of other diseases and conditions that might account for the symptoms being presented (Mendez & Cummings, 2003). Diagnostic criteria, however, previously based on research and findings from twenty-seven years ago, changed in 2011 (Jack, et al, 2011). Accordingly, the new diagnostic protocol begins with a dementia diagnosis in which “cognitive or behavioral (neuropsychiatric) symptoms” have been established, including a declining

functional inability in numerous environments, “not explained by delirium or major psychiatric disorder”, and a diagnosis of “cognitive impairment” in at least two areas (McKhann, et al., 2011, p. 265). Following a dementia diagnosis, AD is confirmed when gradually occurring and worsening symptoms are established with the presence of memory dysfunction and/or additional problems, which may include one or any combination of “language”, “visuospatial”, or “executive function” disabilities (McKhann, et al., 2011, p. 265). Trained, experienced physicians are able to distinguish AD from other dementias with an “up to 90 percent accuracy” using a prescribed set of clinical techniques and medical examinations (U. S. Department of Health and Human Services: NIA/NIH, 2008, September, p. 48). Research advances in the area of diagnostics are especially productive and out-distancing research for both an AD cure and preventative measures, presenting challenges for patients seeking diagnoses and the clinicians evaluating and treating them (Petersen & Trojanowski, 2009).

Since 2004, the NIA, in cooperation with other partners, has been exploring the use of neuroimaging techniques to advance the detection AD at earlier points in time (AD Neuroimaging Initiative [ADNI], 2010). In 57 sites located throughout the U. S. and Canada ADNI is focused on correctly identifying AD before it fully manifests in the generally recognizable debilitating characteristics of dementia (Petersen & Trojanowski, 2009). In one ADNI study, Petersen and colleagues (2010) successfully predicted the progression of AD and the conversion from MCI to AD in neuroimaging tests with cerebrospinal fluid among a total of 819 participants, including those who were diagnosed as “cognitively normal”, others who were diagnosed “with MCI”, and a third group who had an AD diagnosis (p. 201). In a related study, researchers using a similar mixed modeling method of participants who were “cognitively normal”, diagnosed with AD, and diagnosed with MCI, found that AD could be accurately

pinpointed by testing for beta-amyloid and tau protein “biomarkers” in the cerebrospinal fluid of study participants (DeMeyer, et al., 2010, p. 949). While progress in screens and diagnostics for AD are clearly advancing, challenges still exist for treatment once a diagnosis is been made.

### ***Treatment of Alzheimer’s Disease***

While no cure or preventative treatment for AD for currently exists, several prescription drugs are approved for therapeutic, though short-lived use (Alzheimer’s Association, 2010a, March; Mendez & Cummings, 2003; U. S. Department of Health and Human Services: NIA/NIH, 2008, September). To date, five U. S. Food and Drug Administration approved medications, marketed under the names Razadyne, Exelon, Aricept, Cognex, and Namenda, have been shown to provide only a brief delay of approximately one year or less in the disease’s progression (Alzheimer’s Association, 2010b, March ; U. S. Department of Health and Human Services: NIA/NIH, 2010c, July). Prescriptions for Cognex are written infrequently, however, as questions exist about its safe use (U. S. Department of Health and Human Services: NIA/NIH, 2010c, July).

Other potential medications in government and private industry research pipelines are presently in one of the three required and rigorous phases of clinical trials before FDA approval can be granted (U. S. Department of Health and Human Services: NIA/NIH, 2009a, February). According to the Alzheimer’s Association, “approximately 90 experimental therapies aimed at slowing or stopping the progression of Alzheimer’s are [currently] in clinical testing in human volunteers” today (2010b, March, p. 8).

Additional recent developments address long-standing recommendations for prevention and treatment of AD which have consistently emphasized healthy lifestyle choices revolving around diet, physical and mental exercise, and positive social engagement (Alzheimer’s

Association, 2010b, March). Findings from a recently-convened NIH panel report that while such healthy lifestyle choices promote overall good health and reduce the risk for other health conditions, their associated value in preventing AD has not been proven through rigorous enough scientific methods and, as a result, further studies are warranted (U. S. Department of Health and Human Services: NIA/NIH, 2010b, April). While the Alzheimer's Association accepts the NIH panel findings, and agrees that the "relationship between heart health and brain health" is one area in which additional investigation is needed to fully understand the connection between them, it encourages individuals to continue pursuing healthy lifestyles to promote good health and reduce known risk factors associated with chronic illness and diseases such as diabetes that contribute to poor health outcomes (Alzheimer's Association, 2010e, September).

### ***The Caregiving Role***

#### ***The Caregiving Relationship***

According to Calasanti and Slevin (2001) informal care work is two-fold, caring "for" another person and caring "about" that person, implying and involving a connection or bond (p. 145). Pearlin and associates (1990) refer to this bond as the "affective component of one's commitment to the welfare of another", where the act of "caregiving is the behavioral expression of this commitment" (p. 583). The relationship between caregiver and care recipient is at the core of the commitment where both "physical labor" and "emotion work" are primary elements of the caregiving bond (Calasanti & Slevin, 2001, p. 145). Aneshensel and colleagues (1995), however, stress that caregiving relationships are not solely derived from "emotional attachment" as a broad number of factors may bring the caregiver and care receiver together including feelings of obligation and family norms, or a lack of options or a lack of affordable options (p. 25). Neither does emotional attachment fully explain why some members within a family are

more likely than others to engage in caregiving (Aneshensel, Pearlin, Mullan, Zarit, Whitlatch, 1995).

### ***Gender Norms***

Connidis and Kemp (2008) found gender to be an influence within caregiving families and on caregiving roles according to “structural factors” based upon gender (p. 236). They suggest that selecting or “excusing” members for caregiving responsibility is an implicit negotiation between family members in which “socially structured gender relations” are a factor (Connidis & Kemp, 2008, p. 236). Calasanti and Slevin (2001) add that carework is primarily the domain of females who engage in care of both young and old family members, and in part by default. Spouses of either gender, they note, are the typical caregiver with longer female life spans tending to place wives in caregiving roles more than husbands (Calasanti and Slevin, 2001). Still, among other family members, the next choices tend to be daughters and daughters-in-law before sons and sons-in-law (Calasanti and Slevin, 2001). Finally, Stoller (1993) suggests that a combination of factors influence gender norms for caregiving role selection. “Family caregiving, as an experience of obligation, [is] structured by the gender-based division of domestic labor, the invisibility of devaluing of unpaid work, occupational segregation in the work force, and an implicitly gendered work place” (Stoller, 1993, p. 166).

### ***Spillover***

Providing care for a person with a dementia impacts caregivers in various ways and in numerous areas (Aneshensel, et al., 1995; Zarit, 2008). Adults may already be engaged in multiple roles and “spheres”, such as with parenting and paid work, when the additional role of caregiving for an elder is acquired (Mennino, Rubin, & Brayfield, 2005, p. 107). While accommodating the needs of the care recipient and adapting to the new responsibilities of the

role, caregivers may find the effects of “experiences in one role often spill over to affect experiences in another role” (Martire, Stephens, & Atienza, 1997, p. 279). Such a spillover effect may be “positive”, as when caregivers who also are involved in paid work roles experience decreases in “caregiving stress” from “greater financial, social, and psychological resources” (Martire, et al., 1997, p. S286). But, “negative spillover” effects also may occur if conflict between competing “domains” develops (Mennino, et al., p. 107). The combination of paid and unpaid roles, domains, and responsibilities, in particular, may involve conflict as they represent competing interests and demands (Aneshensel, et al., 1995; Frone, Yardley, & Markel, 1997; Martire, et al., 1997; Mennino, et al., 2005).

Frone and colleagues found that “the obligations of one role frequently interfere with the enactment of a second role” by affecting role “performance” (1997, p. 163). Referring to a “work – family interface”, they suggest that these spheres have an “indirect reciprocal” relationship (Frone, et al., 1997, p. 162). They agree that while a positive spillover effect may develop because of “work-related support” or “family-related support”, the reverse may also be true due to “work-to-family conflict” and “family-to-work conflict” (Frone, et al., 1997, p. 162). Time, and its availability or constraints, as well as an ability to focus on the task at hand are two issues that may work to create conflict between domains and stress for the caregiver (Aneshensel, et al., 1995; Martire, et al., 1997; Mennino, et al., 2005). Aneshensel and associates relate conflict and subsequent experiences of stress to “role overload”, an “internal experience” of “being overwhelmed” (1995, p. 80). Role overload can contribute to caregiver burden, a topic discussed in more detail in a later section.

Gender also may influence spillover and the prioritization of responsibility within individual domains (Minnino, et al., 2005). In some instances gender expectations may even

exacerbate conflicts individuals experience within their paid and unpaid work domains or between them (Minnino, et al., 2005). Minnino and associates found that the culture of the paid workplace may influence the degree to which employees experience negative spillover effects from one domain to another as “company policies, in the absence of changed normative expectations,” are not enough to prevent negative spillover (2005, p. 124). Workplace norms according to gender may dictate expectations for responsibility and choice (Minnino, 2005). Aneshensel and associates observed that work, both unpaid and paid, varies according to “gender” (1995, p. 22). They explained that “caregiving careers may well impede the occupational attainments of women, sustaining the very gender stratification of the occupational sphere that channels women into caregiving” (1995, p. 22).

### *The Caregiving Career*

The sphere of informal or unpaid caregiving for an individual with a dementia has been conceptualized as a “career” that entails a reorganization of personal “responsibilities and activities” over a period of time (Aneshensel, et al., 1995, p. 16). It usually evolves in “multiple stages” with corresponding adjustments (p. 17).

Though the term career is often associated with occupations, the work of caregiving can be thought of as a career as well because of its required dedication to the focused activity, which may be long-term. Still, marked differences exist between the two. While an occupational career may be known for its distinct features such as advancements, rewards, and benefits coinciding with achievements and planned stages and goals, a caregiving career lacks these formalities as well as the earned wages that contribute to a “social evaluation” (p. 87).

Caregiving careers are inexplicably linked to familial obligations. Caregivers, in meeting those obligations, undergo changes influenced by their experiences with the care recipient,

including the timing of careers' beginnings and endings (p. 22). Though benefits of caregiving careers may exist and are noted in a following section, the work of caregiving generally is not without the risk or sacrifice of personal stability in matters of finances, and medical and social well-being, generally described as "costs" (p. 334). Aneshensel and colleagues describe the origin of these costs in terms of "stressors" (p. 69). "The conditions, experiences, and activities that are problematic for people, threatening them, thwarting their efforts, fatiguing them, and defeating their dreams" are the stressors that link to both "internal" and "external" causes (p. 69).

### *The Costs of Dementia Care*

#### *Costs of Informal Caregiving: Financial Health*

Informal caregivers bear a tremendous personal responsibility for persons with a dementia and absorb numerous costs (Alzheimer's Association, 2010b, March; Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Rhee, Degenholtz, Lo Sasso, & Emanuel, 2009). For the year 2009, unpaid caregivers contributed approximately 12.5 billion hours in their roles, amounting to a value of nearly \$144 billion, when based upon an \$11.50 hourly rate (Alzheimer's Association, 2010b, March). According to the National Alliance for Caregiving (NAC) in conjunction with the American Association of Retired Persons (AARP) for the year 2009 (as cited by the Alzheimer's Association, 2010b, March), 6 out of 10 informal care providers were at the same time wage workers employed in full or part-time jobs. One result of this dual role is that over time, individuals productive in dementia caregiving may come to be, by default, less productive in other endeavors as caregiving roles typically require increasing hours to meet advancing dementia needs and decreasing care recipient independence (Rhee, et al., 2009; Zhu, Leibman, et al., 2008; Zhu, Scarmeas, et al., 2006). Indeed, employed caregivers

have been found to modify starting and ending times of workdays, as well as total work hours, due to multiplying caregiving responsibilities (Alzheimer's Association, 2010b, March).

Informal caregivers generally vary in age but most are female, accounting for 66 percent of all caregivers (NAC/AARP, 2009). Of the approximate 25 percent of persons with a dementia who are married, only about 6 percent receive care provided by a spouse (Alzheimer's Association/NAC, 2004, p. ii). For "seven out of ten" families, care for a person with a dementia is provided by several family members (Alzheimer's Association/NAC, 2004, p. ii). Among "caregiving relationships", approximately 57 percent of recipients are cared for by offspring (Alzheimer's Association/NAC, 2004, p. 1). Thirty-six percent of caregiving offspring care for the "mother", 11 percent provide care for the "mother-in-law," 8 percent care for the "father," and 2 percent care for the "father-in-law" (Alzheimer's Association/NAC, 2004, p. 1). Of caregivers aged 35 or younger, approximately 14 percent care for persons with AD; of those aged 35 to 49, about 26 percent are AD caregivers; of those between the ages of 50 and 64, nearly 46 percent are caring for individuals with AD; and of those age 65 or older about 13 percent are caring for someone with AD (NAC/AARP, 2009, as cited by the Alzheimer's Association, 2010b, March).

Two implications are immediately noticeable in these statistics. First, as the NAC and AARP point out, a significant number of Alzheimer's caregivers are of wage-earning age (NAC/AARP, 2009, as cited by the Alzheimer's Association, 2010b, March). Second, women appear to be particularly subject to the dual, if not opposing, demands of caregiving and employment, affecting both their current and future earnings (NAC/AARP, 2009, as cited by the Alzheimer's Association, 2010b, March). For families in which two-wage earners are important, a third implication is the increased financial strain that Alzheimer's imposes (Alzheimer's

Association, 2010b, March, p. 30). One estimate finds that informal caregivers assume approximately \$219 each month in “out-of-pocket” expenses (Alzheimer’s Association, 2010b, March, p. 30). Another estimate reports that annual caregiver “out-of-pocket expenses” average approximately \$5,885 for “co-residents” to as high as \$8,728 for caregivers not residing together (Houser & Gibson, 2008, p. 3).

### ***Costs of Informal Caregiving: Caregiver Burden***

***Defining Caregiver Burden.*** Other costs of a personal nature exist for informal dementia caregivers (Alzheimer’s Association, 2010b, March). These personal costs are sometimes referred to as “caregiver burden” (Croog, Burlison, Sudilovsky, & Baume, 2006; Dang, Badiye, & Kelkar, 2008; Spitznagel, et al., 2009; Zarit, 2008, p. 101). Caregiver burden is a complex combination of feelings, thoughts, and encounters related to the work of caregiving (Georges, et al., 2008). Zarit (2008) describes burden in the dual context of “stressors”, both “objective” and “subjective”, that impact caregiving individuals in a broad range of experiences (p. 101). Objective stressors are those with direct connection to the care recipient’s disease process itself, while subjective stressors are caregiver experiences related to that disease process that are problematic for the caregiver (Zarit, 2008). Caregiver burden, linked to problems specifically associated with carework, includes a higher associated risk of depression, as well as increased other psychological and physical problems related in part to the length of “caregiving careers,” (Aneshensel, 1995; Dang, et al., 2008; Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007; Schulz, O’Brien, Bookwala, & Fleissner, 1995). While objective stressors may not be modifiable, subjective stressors may be able to be addressed through interventions and strategies such as use of brief or long-term formal care options for the care recipient and education and supportive counseling for the caregiver (Zarit, 2008).

***Psychological and Emotional Effects.*** One report found “emotional stress” associated with caregiver burden among Alzheimer’s caregivers to be high (Alzheimer’s Association/NAC, 2004, p. 2). In this report, 41 percent of AD caregivers identified “their stress as a four or five” on a “five point scale” (Alzheimer’s Association/NAC, 2004, p. 2). Croog and colleagues (2006) found that among a number of reactions spouses of persons with AD have to caregiving, “anxiety about the future and feeling the need to do more” were most common (p. 95). In regard to responses to specific dementia characteristics, care recipients’ behaviors and emotionality elicited the strongest caregiver reactions, more so than care recipients’ problems with cognition (Croog, et al., 2006; Etters, Goodall, & Harrison, 2008; Papatavrou, et al., 2007). Burden-inducing characteristics were found to involve aggressive or agitated behavior and incidences of “nighttime wandering” (Etters, et al., 2008, p. 425). In one study, caregivers were most likely to react to such behaviors by becoming angry at and resentful of their care recipients (Croog, et al., 2006).

Other psychological and emotional experiences of burden are associated with relationship role changes (Adams, 2006). Give and take, shared responsibilities and intimacies, and reliance between couples, as well as parents and adult children, all become redefined by the progressing limitations of the dementia (Adams, 2006). Providing care to a person with a dementia “can have a strong influence on family relationships” (Etters, et al., 2008). Relationship changes may occur not only between caregiver and care recipient, but in a larger scope, the extended family members (Aneshensel, et al., 1995).

“Conflict” may be one outcome of stress within a family when members are involved in caregiving and care receiving (Aneshensel, et al., 1995, p. 85). Gwyther (1998) suggests that family life with a dementia “implies a permanent imbalance” in which “adjustments and

adaptations must be made by the family” (p. 17S). Disagreements may revolve around individual members’ assessments of the care recipients’ disease, caregivers’ assessments of family members’ involvement, and issues related to caregiver recognition (Aneshensel, et al., 1995). Dual and simultaneous caregiving responsibilities for both persons with AD and minors younger than “age 18,” represent another potential type of family conflict (Alzheimer’s Association, 2010b, March, p. 26; Dang, et al., 2008). Altogether, family disagreements about how to help, or how and when to seek assistance, may lead to caregiver isolation and psychological effects of burden (Lyons, et al., 2000).

In many respects, aspects of caregiver burden may be similar for caregivers of elders as a whole and dementia caregivers. A longitudinal study utilizing a sample of 37,742 participants from the original Nurses’ Health Study found that caregivers new to caring for spouses or parents tended to experience “declines in mental health status”, including depression and anxiety, more than non-caregivers, current caregivers, and those who were no longer providing care to similar recipients (Cannuscio, et al., 2002, p. 1307). The amount of time committed to caregiving responsibilities was also found to correlate to an increased risk to mental health status among all caregivers (Cannuscio, et al., 2002). Gaugler and Teaster (2006) refer to this risk as the “wear and tear hypothesis” (p. 143). Mental health status is also associated with physical health status so that caregiving careers may pose other health risks to a substantial proportion of Americans (Cannuscio, et al., 2002).

***Physical Effects.*** In a meta-analysis of literature regarding caregiver burden related to caring for individuals with some form of dementia, Schulz and colleagues (1995) reported findings from 41 studies. They noted that “health care utilization” was more informative about “physical health status” than individual “self-report[s]” (p. 781). Their analysis concluded that

caregivers of persons with a dementia received physical healthcare services more often than other caregivers, including hospitalizations and “physical exams” (p. 781). Conditions reported ranged from difficulty sleeping to declining immunity and several heart-health related factors, including higher “systolic blood pressure” and “triglycerides, and “lower high-density lipoprotein [HDL] cholesterol” levels (p. 782). They also reported that physical effects of caregiving also had some effect on psychological health, as caregivers with “poorer physical health” experienced more “psychological distress” (p. 783).

Results from the later Framingham Coronary Heart Disease (CHD) Risk Score also report that caregivers of persons with a dementia are at greater risk for poorer physical health, including CHD (von Kanel, et al., 2008). Participants in this study were found to have higher blood pressures, even when medications to control the condition were routinely used. They were also found to have more symptoms of depression and “role overload” than those not engaged in caregiving (p. 134).

***Social Effects.*** Etters and associations (2008) found that caring for a person with a dementia is linked with a decline of “social support” and “social life,” limiting caregiver well-being and increasing caregiver burden (p. 425). Sanders (2007) agreed, finding that caregivers experienced waning support as their care-receivers’ dementias progressed.

Other effects may arise from experiences of stigma, defined as a diminished value assigned to persons exhibiting unwelcome traits (Corrigan, Markowitz, Watson, Rowan, & Kubiak, 2003). One qualitative study of 30 care-receiver/caregiver dyads found a correlation between a diagnosis of dementia and stigma (Aminzadeh, Byszewski, Molnar, & Eisner, 2007). Both care-receivers and caregivers acknowledged that revealing a dementia diagnosis created immediate questions about care-receivers’ abilities to function, leading some dyads to conceal

diagnoses (Aminzadeh, et al., 2007). Werner and Heinik (2008) also found a change in demeanor of others toward the person with dementia in their qualitative study of 61 AD caregivers. Caregivers were also found to actively suppress revealing a dementia diagnosis to people they knew (Werner & Heinik, 2008).

***Mediating Positive Effects.*** Some caregivers, regardless of caregiving situation, experience fewer negative or stressful effects (Pearlin, et al., 1990). Sense of “satisfaction,” may be one mediating factor according to Andren and Elmstahl (2005) who found that among dementia caregivers, satisfying caregiving experiences may act as a foil against negative experiences of burden (p. 165). Campbell and colleagues (2008) note that some positive feelings are rooted in caregivers’ own “coping” skills and the “relationship quality” with their care-receivers (p. 1082). Positive caregiving experiences also may be related to feelings of enrichment as caregivers develop deepening relationships to their care-receivers and increased skill in their “role[s]” (Dang, et al., 2008, p. 1247). Cooper and associates suggest that caregiver use of “coping strategies” is important, finding that differences exist among strategy types (2008). “Coping” may be defined as “behaviors and practices” caregivers use for their own benefit (Pearlin, et al., 1990, p. 590). Caregivers’ use of strategies to address care recipient behaviors, however, may be less effective than strategies used to address care recipient emotions and therefore more effective in providing stress reduction for caregivers (Cooper, Katona, Orrell, & Livingston, 2008).

### ***Societal and Economic Cost of Caregiving***

The Alzheimer’s Association notes that persons who have AD utilize formal or paid care services at a higher rate than others who require formal care (May, 2010c). They report that without the advent of more advanced and reliable treatments, a cure, or preventative measures,

expenses for AD care will rise dramatically from \$172 billion in 2010 to surpass the \$1 trillion mark by the year 2050 (Alzheimer's Association, 2010c, May). At the same time, costs associated with Medicare may be expected to rise to more than 600 percent, from approximately \$88 billion at the present time to roughly \$627 billion by 2050 (Alzheimer's Association, 2010c, May). Medicaid expenses in the same period may be expected to rise about 400 percent from \$34 billion today to about \$178 billion (Alzheimer's Association, 2010c, May). Crucial to understanding these figures is the fact that by 2050 approximately 48 percent of those predicted to have AD will have progressed to the most acute phase of the disease when costlier and more demanding care can also be predicted to be required (Alzheimer's Association, 2010c, May).

Other societal costs associated with dementia which may be expected to occur include an insufficient number of available formal care providers such as geriatricians, geriatric pharmacists, and nursing and social service workers, and the services that they offer (Alzheimer's Association, 2010b, March). The 2008 *Institute of Medicine Report* (as cited by the Alzheimer's Association, 2010b, March), notes that for the year 2007, geriatric MDs numbered 7,128 and geriatric psychiatrists totaled 1,596. Growth of the age 65 and older population will necessitate growth within the medical profession, such that an estimated 36,000 geriatric physicians alone will be needed by the year 2030 (Alzheimer's Association, 2010b, March).

### ***Long-Term Care***

#### ***Defining and Describing***

Long-term care may be defined as care that is supportive rather than curative and that seeks to address a broad range of needs for individuals unable to meet those needs on their own, including “activities of daily living ADLs” and “instrumental activities of daily living IADLs”

(Chen, 2006, p. 870). Generally, individuals may receive LTC to address needs resulting from a wide array of causes, including those directly associated with development of a dementia.

Several different types of care exist that may be described as LTC (Johnson, et al., 2007; Kelsey, et al., 2010). These vary from informal care, such as family caregivers, to use of in-home paid caregivers to residential care in locations outside the home, such as “assisted living facilities [ALFs] and nursing homes [NHs]”, among others (Johnson, et al., 2007, p. 4). LTC also includes respite care and hospice, or end-of-life care, two types of formal services providing broad scopes of care taking place either in the home or other residential setting (Wacker & Roberto, 2008). Respite care services provide temporary targeted care to recipients while at the same time addressing needs caregivers have for interval breaks from carework responsibilities and associated caregiver burden (Wacker & Roberto, 2008). Hospice services address the end-of-life supportive care needs of both individuals with terminal illnesses and their families and is typically short-term in nature, averaging “59 days” or less (Wacker & Roberto, 2008, p. 343). The topics in this section will focus on formal LTC alternatives to informal caregiving, as these may be choices that informal caregivers consider when contemplating or choosing assistance.

### ***In-Home Long Term Care***

Choices of formal care in the home setting may include the use of trained home health aides or “nonmedical” assistants for routine, intermittent (respite), or hospice services (Wacker & Roberto, 2008, p. 331). In-home LTC choices may provide care that is less expensive than LTC outside the home, depending on the level of care required, the number of services provided, and the length of time formal care assistance is required (Wacker & Roberto, 2008). Wacker and Roberto (2008) note that among many older individuals, in-home residential care is favored over residential care occurring outside of the home.

Recent surveys found that 10,800 providers of home health services, 2,200 providers of hospice services, and 1,400 providers of a combination home health and hospice services (Centers for Disease Control [CDC], 2007a) were caring for a total of 1.46 million clients (CDC, 2007b). At the same time, Medicare was found to most frequently provide payment to home health services and a combination of home health and hospice providers, by 56 percent and 66 percent respectively (CDC, 2007a). Twelve percent of home health services were found to be covered by individual insurance plans, while 17 percent of clients self-paid providers of a combination services (CDC, 2007a). The survey noted that Medicaid provided 22 percent of payments to home health providers, but only 10 percent of payments to providers of combination services (CDC, 2007a). For providers of hospice-only services, Medicare was found to pay 81 percent of charges versus 66 percent of charges for combination service providers (CDC, 2007a).

#### ***Adult Day Services.***

Adult day services may be described as group programs that provide temporary supervision outside the home setting (National Adult Day Services Association [NADSA], 2010). They may address care recipient socialization, and in some instances, health-related matters (NADSA, 2010). Programs of this type are a unique form of respite LTC in which care recipients continue to live at home, but receive formal services outside the home (NADSA, 2010). According to NADSA (2010), 4,601 U. S. programs currently provide adult day services to more than 150,000 individuals daily, of whom approximately 52 percent are cognitively impaired. Of these programs, about 22 percent operate privately, while the bulk of them operate publicly with third party financial assistance, including donations and municipal funds (NADSA, 2010). Fees among all adult programs nationally average about \$61 daily for a typical 8 to 10 hour day (NADSA, 2010). In the state of Georgia, average daily fees range between \$48 and

\$60 in the greater metropolitan Atlanta area, with an average daily fee range in the rest of the state found between \$57 and \$63 (MetLife, 2008a).

### ***Residential Long Term Care Outside the Home***

Residential LTC existing outside the home includes numerous types of settings from which a choice may be made for those requiring assistance to meet their needs, including needs associated with a dementia. Assisted living facilities, NHs, and MCUs, existing as stand-alone facilities or associated with either an ALF or NH, are among the variety of choices that may be considered (Kelsey, et al., 2010; Wacker & Roberto, 2008). Typical supportive services found in both ALF and ALF-associated MCU settings generally include supervised oversight around the clock, assistance with ADLs and IADLs, meal services, opportunities for socializing, and minimal health support (Wacker & Roberto, 2008). Nursing homes and NH-associated MCUs typically offer a variety of in-residence services, including “restorative, rehabilitative, and medical” care which may be received along with meal services, and supervision (Wacker & Roberto, 2008, p. 365). Because ALFs, NHs, and MCUs are most closely associated with the present study, these settings are included here and described in greater detail.

***ALFs.*** A LTC option modeled after elder care in Scandinavia, ALFs first began appearing in the U.S. mid-decade in the 1980s (National Center for Assisted Living [NCAL], 2001). ALFs in this country today are known for offering a range of long-term assistance and caregiving in “congregate settings” (Johnson, et al., 2007). Ball and associates (2009) describe assisted living as a “middle-ground alternative” between the home and nursing home care (p. 104). Noting that assisted living is difficult “to define,” Polivka (2010) explains that assisted living encompasses a broad assortment of types according to variables such as “size, service provision, regulatory standards, funding sources, and resident characteristics” (p. 28). This

diversity, he continues, is part of what makes uniformly defining assisted living difficult for researchers or regulating bodies (Polivka, 2010). Another perspective of assisted living describes it as being more of “an approach” toward “long-term care”, rather than a place for LTC, where respect for impaired individuals and their autonomy is a key element (Hyde, Perez, & Reed, 2008, p. 48). One aspect of the LTC approach is the availability of focused support for residents’ desires and needs “to maintain a sense of continuity” even as they experience life changes (Perkins, Ball, Hollingsworth, & Whittington, Manuscript submitted for publication). Presently, nearly one million individuals reside in roughly 38,000 ALFs across the country that are individually categorized, defined, and regulated by their home state regulatory bodies (NCAL, 2010a; NCAL, 2010b, March).

In the state of Georgia, ALFs are identified as a type of “personal care home [PCH]” (Department of Community Health, Division of Healthcare Facility Regulation [DCH, DHFR], Georgia, 2009; Georgia Assisted Living Federation of America [ALFA], 2010). Though a variety of congregate living arrangements are included in the PCH designation, all fall under this state of Georgia general definition:

Any dwelling, whether operated for profit or not, which undertakes through its ownership or management to provide or arrange for the provision of housing, food service and one or more personal services for two or more adults who are not related to the administrator by blood or marriage (DCH, DHFR, Georgia, 2009, p. 45).

PCHs in the state of Georgia exclude the direct provision of skilled nursing services, the domain of NHs (DCH, DHFR, Georgia, 2009).

“Personal care services” are comprised of, though “not limited to, individual assistance with or supervision of self-administered medication, assistance with ambulation and transfer, and essential activities of daily living such as eating, bathing, grooming, dressing, and toileting” (DCH, DHFR, 2009, Georgia, p. 45). An “adult” for the purpose of the PCH definition is identified as a person of the age of 18 or older (DCH, DHFR, 2009, p. 44).

The number of PCHs in the state of Georgia has grown steadily over the years (Mollica, Sims-Kastelein, & O’Keeffe, 2007). For the year 2002, available statistics show that 1,648 facilities (25,563 units) were in operation and that by 2007 those numbers had increased to 1,860 facilities offering 26,500 units (Mollica, et al., 2007). According to Georgia’s DCH, DHFR (2009), as of August 30, 2010, approximately 2,222 PCHs were operating in Georgia (Personal communication, 2010, August 30).

Though AL may be paid for in a number of ways, most rates and fees are paid through private funds (Assisted Living Federation of America [ALFA], 2008). The ALFA states that approximately 50 percent of “payment sources” are self-pay, while approximately 33 percent of payments are made through family sources (2008, p. 8). Qualifying yearly incomes of \$25,000 to \$35,000 are found to be average for residents according to one source (Dixon Hughes, 2009). The ALFA, however, notes that the “median income” of residents is \$15,686, while residents’ “median assets” is approximately \$250,000 (2008, p. 4). Though used less often, other sources of payment are found, including Medicaid state reimbursement, which is estimated to occur in just over 8 percent of instances (ALFA, 2008). Additional types of payment that may be used include insurance policies, used in approximately 3 percent of instances, Supplemental Security Income, used just over 1.5 percent of the time, and Veterans Administration benefits applied

only 0.7 percent of the time (ALFA, 2008). In the state of Georgia, “a Medicaid home and community-based services waiver” is utilized in some instances (NCAL, 2010, p. 41).

Resident costs in PCHs vary in part due to dissimilar monthly base rates, and in part because of individually charged supplementary fees for the variety of personal care services residents may receive in addition to available base services (MetLife, 2008b). Nationally in 2008, monthly ALF base rates averaged approximately \$3,031 (MetLife, 2008b). For the same time period, supplementary fees covering personal care services not already offered in a resident’s monthly base cost averaged nationally an additional \$327 for ADL services and \$386 for IADL services (MetLife, 2008b). Corresponding monthly base costs for Georgia PCH residents in 2008 averaged approximately \$2,732 where a statewide range of base costs ran from approximately \$1,850 to \$3,600 a month (MetLife, 2008b). Average costs for supplementary services in the state of Georgia were not available.

Typical AL residents are older adults of about 85 years of age, reside by themselves, and require some level of both ADL and IADL assistance (ALFA, 2008; Dixon Hughes, 2009; Zimmerman, et al., 2003), but not the higher level of care found in nursing homes (Zimmerman, et al., 2003). Women number approximately three-fourths of all AL residents (ALFA, 2008; Zimmerman, et al., 2003) and most are white (Zimmerman, et. al., 2003).

Assisted living residents require and receive a number of services. The ALFA notes that approximately 68 percent of all AL residents require assistance “bathing” and nearly half of all AL residents need help with both “dressing” and bathing (2008, p. 6). Approximately one-third of residents need assistance with “toileting” and transferring help is necessary for one-fourth of residents (2008, p. 6). Approximately 78 percent of residents can rely upon their own skills at meals and do not require aid when eating, but approximately 86 percent of “AL residents”

require medication management services from their facility (ALFA, 2008, p. 6). Younger AL residents in their 70s are frequently those with disabilities that impact their independence or are those who are without the assistance of caregivers from other sources (Dixon Hughes, 2009). Chronic illnesses or conditions are common among AL residents with only about 10 percent of residents estimated to have none (Hyde, Perez, & Reed, 2008). Because standard AL support includes the provision of prepared meals and housekeeper services, actual need for this type of support is not accurately reflected by number of residents who receive them (NCAL, 2001).

Reports of levels of dementia in AL residents vary. One study found between approximately 23 percent and 42 percent of AL residents with some level of “cognitive impairment” (Zimmerman, et al., 2003, p. 113). The broad range is attributed in part to the type and size of ALF, where “smaller facilities consistently housed the most impaired residents and traditional facilities consistently housed the least impaired” (Zimmerman, et al., 2003, p. 113). A later review of studies assessing levels of dementia in AL, however, found reported levels varying from approximately 27 percent to roughly 67 percent (Hyde, Perez, & Forester, 2007). Among the reviewed studies, Hyde and colleagues note that the figure of a lesser amount (27 percent) of dementia in AL was comprised of instances of “moderate/severe” only, with no data regarding “mildly demented residents” having been included (Hyde, et al., 2007, p. 53). Another of the reviewed studies found 45 percent of residents with some type of dementia by surveying AL provider accounts (Hyde, et al., 2007). The higher reports of dementia from two other reviewed studies, 45 – 63 percent and approximately 67 percent respectively, were similar to Zimmerman and colleagues’ (2003) findings that higher percentages of dementia are found in residents of smaller (fewer than 16 residents) AL settings (Hyde, et al., 2007). The Alzheimer’s Association also notes that variance among studies explains the differences in the prevalence of

dementia in AL by noting that “the way residents with Alzheimer’s disease and other dementias are identified” accounts for differences in findings (2004, n. p.). However, their Advocacy and Public Policy Division states that “half or more of all elderly assisted living residents have Alzheimer’s disease or other dementias” (Alzheimer’s Association, 2004, n. p.).

***Nursing Homes.*** More often than not, LTC in NHs is utilized as a last option among many (Wacker & Roberto, 2008). Though some residents enter NHs temporarily for a period of recuperation that requires medical care, most residents enter NHs because their multiple and varied care needs are beyond the scope of other types of LTC (MetLife, 2008b).

Nursing home residents experience a greater number of ADL “functional impairments” than others in LTC (Zimmerman, et al., 2003, p. 114). According to a CDC report, 51.1 percent of NH residents require “assistance in all five ADLs”, including “bathing, dressing, toileting, transferring, and eating” (U. S. Department of Health and Human Services, CDC, 2009, pp. 4, 6).

In a comparison of NH residents to AL residents, approximately 83 percent of NH residents in were found likely to require some type of ADL assistance compared to 15 - 37 percent of AL residents or those residing in other types of LTC (Zimmerman, et al., 2003). Some similarities do exist between NH and AL residents, however, in regard to presence of a “heart condition” as approximately 48 percent of NH residents, compared to between 38 - 49 percent of those residing in ALFs or other types of LTC are noted to have some form of cardiac ailment (Zimmerman, et al., 2003, p. 114). A CDC report notes that “diseases of the circulatory system were the leading primary diagnoses among [NH] residents at admission” (U. S. Department of Health and Human Services, CDC, 2009, p. 4).

The prevalence of cognitive impairment in the NH population varies according to source and year published. An early study notes that approximately 70 percent of NH residents have

“short-term”, “long-term”, or “long-and short-term” memory deficits (U. S. Department of Health and Human Services, Agency for Healthcare Research and Quality (AHRQ), 1996, p. 9). More than 50 percent of these NH residents are noted to have both long-and short-term problems (U. S. Department of Health and Human Services, AHRQ, 1996, p. 9). A later study reviewing findings from 40 NHs, found a comparable approximate 51 percent of NH residents to have some form of cognitive impairment, noting that cognitive impairment is higher among NH residents than AL residents (Zimmerman, et al., 2003).

A CDC report, relying on data from *The National Nursing Home Survey: 2004 Overview*, states significantly fewer instances of dementia, noting instead that between 16.4 and 21.9 percent of NH residents have a “mental disorder”, a term used in the report that broadly includes varying types of cognitive impairments in addition to dementia (U. S. Department of Health and Human Services, CDC, 2009, p. 28). This same CDC report notes that an additional 14 percent of NH residents have “diseases of the nervous system and sense organs”, a designation that includes among other conditions, Alzheimer’s disease (U. S. Department of Health and Human Services, CDC, 2009, p. 28). A column written for the Center for Excellence in Assisted Living comments on the disparity of findings by stating that “an underestimate [of] the prevalence of dementia in assisted living and nursing homes” exists, referring to findings from *The National Nursing Home Survey: 2004 Overview* (2007, n. p.).

Ability to pay for needed services may be a strong factor in choosing NH care over other types of LTC settings as a high number of NH users are also Medicaid-eligible (Georgia Department of Community Health, 2010). Though similar to AL residents covered in an earlier section, multiple sources are used by residents to pay for NH services. A Centers for Disease Control (CDC) report states that “it is not unusual for [NH] residents to have access to more than

one source of payment” and that use of payment sources varies (2009, p. 4). This same report also notes that approximately 42 – 66 percent of residents utilize private pay resources to some extent, while between more than 12 percent to just over 36 percent of residents make use of Medicare, though nearly 39 percent to more than 59 percent rely on Medicaid (U. S. Department of Health and Human Services, CDC, 2009, p. 4). An additional 2.9 - 3.6 percent of residents were found to have undefined “other sources” of payment (U. S. Department of Health and Human Services, CDC, 2009, p. 5).

Demographically, residents of all types of LTC, including NHs, are similar (U. S. Department of Health and Human Services, CDC, 2009; Zimmerman, et al., 2003). Residents are likely to be white, female, unmarried, and roughly half are found to be age 85 or older (U. S. Department of Health and Human Services, CDC, 2009; Zimmerman, et al., 2003).

For the year 2008, 15,730 NHs were in operation across the country representing an available 1,703,846 beds (U. S. Department of Health and Human Services, CDC, 2010a, January, p. 399). In the same year, 359 of these NHs were located in Georgia, representing 39,762 available beds (U. S. Department of Health and Human Services, CDC, 2010a, January, p. 399).

Georgia’s Office of Regulatory Services (ORS) provides two relevant descriptions of NHs. First, a NH is defined as:

A facility which admits patients on medical referral only and for whom arrangements have been made for continuous medical supervision; it maintains the services and facilities for skilled nursing care, rehabilitative nursing care, and has a satisfactory agreement with a physician and dentist who will be responsible for the general medical and dental supervision of

the home (Georgia Department of Human Services [DHS], ORS, 2010, p. 1)

Second, Georgia's ORS states that skilled nursing care:

Means the application of recognized nursing methods, procedures, and actions directed toward implementation of the physician's prescribed therapeutic and diagnostic plan, detection of changes in the human body's regulatory system, preservation of such body defenses, prevention of complications, and promotion of emotional well-being (DHS, ORS, 2010, p. 1).

Nationally, NH base rates according to a 2008 survey average between \$191 and \$212 daily, depending on whether an individual resides in a semi-private or private room (MetLife, 2008b). Annually, these national base rates for the year 2008 averaged from \$69,715 to \$77,380 (MetLife, 2008b). In the state of Georgia for the same year base rates averaged \$159 daily for a semi-private room and \$171 daily for a private room (MetLife, 2008b). Yearly, for the same time period these base rates averaged \$58,035 for a semi-private room to \$72,415 for a private room (MetLife, 2008b). According to the Georgia Department of Community Health (2010), charges incurred by about 74 percent of NH residents are paid by Medicaid.

**MCUs.** Kelsey and colleagues (2010) describe MCUs as "specialized supportive environments for persons with ADRD [AD or a related dementia]" which may be stand-alone or associated with other LTC environments such as ALFs or NHs (p. 255).

Presently, nearly 50 percent of this country's ALFs have been identified as stand-alone facilities offering specialized memory care environments or are ALFs with units specifically for the care of individuals with a dementia (Hyde, et al., 2008). Of those ALFs with attached MCUs, approximately 22 percent of property residents are found to reside within the MCU

setting (Hyde, et al., 2008). Still, just an average of 30 percent of individuals with some type of dementia, including AD, reside in a LTC dementia-specific environments while most others remain within their own communities (Hyde, et al., 2008). In Georgia, an estimated “eight ALFs” are stand-alone memory care properties, while just over 30 percent of the state’s ALFs offer separate MCUs (Ball & Perkins, 2010, p. 65).

In Georgia, ALF MCUs afford a modified living arrangement within the PCH model, according to the DCH, DHFR, Georgia, (2009). Georgia’s state PCH regulations govern its MCUs and cover particular aspects of the physical environment, care of residents, staff requirements, and general policies (DCH, DHRF, Georgia, 2009). Two relevant terms define facilities designated to address memory care needs (DCH, DHRF, Georgia, 2009). The first of these, “memory care services” is described as:

The additional watchful oversight systems and devices that are required for residents who have cognitive deficits which may impact memory, language, thinking, reasoning, or impulse control, and which place the residents at risk of eloping, i.e. engaging in unsafe wandering activities outside the home (DCH, DHFR, Georgia, 2009, p. 44).

The second term, “memory care unit”, is defined as:

The specialized unit or home that either holds itself out as providing additional or specialized care to persons with diagnoses of probable AD or other dementia who may be at risk of engaging in unsafe wandering activities outside the unit or home (eloping) or charges rates in excess of those charged other residents because of cognitive deficits which may place the residents at “risk of eloping” (DCH, DHFR, Georgia, 2009, pp. 44).

MCU residents are subject to experiencing the same types of impairments and disabilities found among other older adults residing in other types of living environments, in addition to cognitive impairment (Hyde, et al., 2008). However, cognitive impairment may contribute to behaviors and difficulties not easily addressed in non- memory care environments, creating “triggers” for transfer from ALFs to MCUs (Kelsey, Laditka, & Laditka, 2008, p. 358). Such triggers may include “wandering”, verbal or physical “negative behaviors”, and accelerated care needs beyond the scope of ADL and IADL assistance provided in the AL setting (Kelsey, et al., 2008, pp. 358-359). Other triggers may include safety issues and lack of engagement in activities or social settings, two areas that memory care environments typically strive to address for those with cognitive impairments (Kelsey, Laditka, & Laditka, 2009). Transfers into settings specifically designed for residents with dementia, however, are not without difficulty, particularly for family members who may resist such change (Kelsey, et al., 2009). One study noted that nearly 50 percent of administrators working at “ALFs with MCUs” experienced “family resistance” to transfers to a dementia care setting (Kelsey, et al., 2009, p. 198). Those administering stand-alone ALFs were less likely to experience family resistance to the transfer (Kelsey, et al., 2009).

Though fewer NH-associated MCUs exist compared to ALF-associated MCUs, NH-associated MCUs are found to be increasingly available with approximately “8 – 10 percent of nursing homes” currently providing this type of specialized care, according to Wacker & Roberto (2008, p. 374). Residents in NH MCUs are described as having fewer care needs related to ADLs than to dementia “behavioral” issues compared to NH residents not residing in MCUs (Wacker & Roberto, 2008). In addition, residents in NH special care units, such as a MCU, are more often found to be “younger, white, and male” (Wacker & Roberto, 2008, p. 374).

Cost-related differences exist between ALF-associated MCUs and NH-associated MCUs. Though average yearly base rates charged for ALF MCUs in the state of Georgia were not available, national average yearly base rates for the year 2008 were listed as \$51,204, or \$4,267 monthly, for separate units and programs for the cognitively impaired located in ALFs (MetLife, 2008b). Average national base rates for the year 2008 for MCUs located in NHs were found to be higher with yearly rates found to be approximately \$72,270 or \$198 daily for a semi-private room and \$79,935 yearly or \$219 daily for a private room (MetLife, 2008b). Generally, monthly rates for MCUs compared to rates for ALFs are “approximately \$1,000 more” (Hyde, et al., 2008, p. 54). However, as noted earlier, types of payment accepted by ALFs compared to NHs also differs as ALFs, and therefore ALF-associated MCUs, primarily accept private payment while both Medicaid and Medicare benefits are available to qualified NH, and therefore NH-associated MCU residents, as are LTC policies, and private insurance (NCAL, 2001; Wacker & Roberto, 2008).

### ***Factors for Caregiver Use of Formal Long Term Care***

A variety of stressors may lead informal caregivers to seek out formal care assistance or solutions (Kelsey, et al., 2010; Lyons, et al., 2000; Spitznagel, et al., 2006). Gaugler and colleagues (2005) suggest that the use of formal LTC is attributable in part to caregiver “wear-and-tear” over the length of the career (p. 78). As caregivers’ careers evolve and develop in response to their care recipients’ changing or growing needs, caregivers may experience personal difficulties (Gaugler & Tester, 2006). Particularly for those involved in dementia caregiving, experiencing a growing and “permanent [relationship] imbalance” may require a lifestyle of constant adjustment (Gwyther, 1998). Responses to carework, cumulative “stress and burden”, and changes to personal health, may lead some caregivers to seek formal LTC solutions

(Gwyther, 1998, p. 18S). However, caregivers with more education and those who receive more support and encouragement are more likely to make use of paid LTC services than those caregivers with less of either (Hong, 2010). Spitznagle and associates (2006) found that caregivers who know more about issues related to cognitive impairment may also seek institutionalization, suggesting that those with greater “knowledge about [a] dementia” prognosis may seek formal services proactively (p. 18).

### ***Factors for Resistance to Use of Formal Long Term Care***

Still, resistance to use of formal LTC services among caregivers does exist and is found to be related to a variety of factors (Hong, 2010; Kelsey, et al., 2010). An ability to pay privately or access coverage for services either through private insurance programs or Medicaid presents a critical barrier to formal LTC use (Hong, 2010). Availability of needed services in proximity to caregivers and care recipients is another factor that Hong (2010) found limits formal LTC service use. Limited formal LTC use may also occur among care-receivers who have higher numbers of caregivers sharing the care workload, as well as those who have use of home modifications and assistive aides, especially for “personal or nursing care” needs (Hong, 2010, p. 96). Some other types of formal LTC have also been found to be generally under-utilized by caregivers as a whole, such as adult day programs and respite care services (Hong, 2010).

Among some caregivers, use of formal LTC outside the home may violate cultural or family norms (Winslow and Flaskerud, 2009). Winslow and Flaskerud (2009) found that some African-Americans and Latinos view LTC outside the home to be culturally unacceptable, choosing to institutionalize family members only as a last resort. They found that some minority families hold strong cultural beliefs that carework is family work, rather than the responsibility of hired workers and institutional programming (Winslow & Flaskerud, 2009). Among other

caregivers, they found that strong concerns about formal workers' cultural sensitivity reinforced the need for families to care for their family members themselves (Winslow & Flaskerud, 2009). Especially important cultural aspects for families were food choices, religious or spiritual expressions, and alternate therapy choices that formal service providers might not be able to honor (Winslow & Flaskerud, 2009). Additional family concerns were found to include a lack of formal care workers able to speak or understand the language of the care recipient or whose racial identity might differ from the care recipient (Winslow & Flaskerud, 2009).

One study co-sponsored by the Alzheimer's Association and the NAC (2004) surveyed the general use of a variety of formal LTC services, finding that low usage exists in a number of areas. Privately hired home workers, including assistants and nurses, were found to be used by 13 percent or fewer caregivers (Alzheimer's Association/NAC, 2004). Among home assistants or nurses hired through an agency, this figure increased, however, to 36 percent for AD caregivers and 23 percent for caregivers of those without AD (Alzheimer's Association/NAC, 2004). Approximately 16 percent of caregivers of individuals with AD were found to use adult day programs, while just 2 percent of caregivers of persons without AD used these services (Alzheimer's Association/NAC, 2004). Respite care was only used by about 9 percent of AD caregivers and 5 percent of caregivers of those without AD (Alzheimer's Association/NAC, 2004). Overall, approximately 53 percent of caregivers of individuals with AD retained "one or more paid services", while those caring for persons without AD utilized paid services approximately 41 percent of the time (Alzheimer's Association/NAC, 2004). Access to formal LTC services, caregiver utilization, and factors such as availability and dissemination of general information and education are issues for providers and policy makers to consider in order to appropriately address community healthcare needs.

### *Literature Regarding Decisions for Moves to Memory Care*

The literature solely regarding moves to MCUs is sparse. Therefore, studies regarding moves to ALF and NH settings, which are relevant to this study, are included in this section as they contribute to understanding the complexity of decision-making for moves to congregate care settings.

Described as “pathways,” Ball and associates (2009) found that individuals’ processes of decision-making for care recipients’ moves to AL vary greatly according to a number of influential factors and issues of “race and class” (pp. 81). Factors including families, finances, disabilities, and previous settings may exert a pushing influence or a pulling influence in regard to decisions for moves. Factors influencing a “push” for decisions to move were found to correlate mainly with instances of “increasing disability” when solutions to significant problems were restricted by choice limits (p. 101). “Pull factors” were found to relate to a more open and positive experience of choice, where options existed in regard to the “timing of decision-making, the type of facility chosen, and the living and care arrangements” sought (pp. 102, 104). Overall, race was found to have less influence on decision-making among those individuals and families when care-seeking individuals and care providing locations were of “comparable socioeconomic status” (p. 102).

In an earlier study of moves made by African –American elders to six ALFs, decisions for moves were found to be the product of many aspects, reflected in the perspectives of caregivers and care recipients, together or separate (Ball, et al., 2005). Finances and changing circumstances and abilities impacted the timing of “how, why, when, and by whom” decision-making occurred (p. 65). For most, a combination of circumstances over a sustained period of time contributed to making decisions for the moves. Especially influential upon decision-

making were the seriousness of the circumstances related to the care recipient and the available care alternatives to address them. These decisions were most often made by family caregivers on the behalf of their care recipients, though some elders made their own decisions to move.

Mead and colleagues (2005) found evidence of care recipients being involved to “varying degrees” in both process and timing of move decisions (p. 119). However, in a study focusing on the “autonomy” of 215 persons with a dementia, Menne and Whitlatch (2007) found that for persons who are increasingly cognitively and physically impaired, “decision-making involvement” is generally decreased (pp. 810, 817).

Armstrong (2000) found that decisions for moves were difficult and complicated. In a qualitative study of two spousal caregivers and two offspring caregivers of persons with a dementia, caregivers rejected the idea of long-term placement (specified only as “residential care” in this study) until they were no longer able to continue providing care at home (p. 34). None of the participating caregivers considered formal care in the home to be a “helpful” option by any of the caregivers (p. 37). They also shared a common belief that formal care workers had a lack of “training” and understanding, believing that not only was there was no benefit to having formal care workers in the home, but utilizing formal home care did not delay decisions for institutionalization (p. 37). Caregivers provided several reasons for eventually choosing LTC for their family members including experiences related to “incontinence,” transferring, bathing, and care receivers’ responses of “verbal and physical aggression” and experiences of “confusion” (p. 35). Similar to Kelsey and colleagues’ (2010) findings examined later in this section, Armstrong (2000) found a desire among caregivers for more information to help them understand their experiences with dementia.

Among those with a dementia participating in their own move decisions, Mead and colleagues (2005) found that individuals were involved to “varying degrees” in both process and timing when decisions were related to remaining in the broader LTC setting or transferring to a MCU (p. 119). Focusing on the “autonomy” of persons with a dementia, Menne and Whitlatch (2007) found in their study of 215 participants, that for persons who are increasingly cognitively and physically impaired, “decision-making involvement” is generally decreased (pp. 810, 817).

Kemp (2008) explored the course of married couples making moves to assisted living, finding that remaining coupled was significant to spouses’ perceptions of well-being whether their abilities were alike or different. She noted that couples often made moves to formal LTC after exhausting alternatives in the home setting and that for many of these couples, decisions surrounding these moves were shaped by attitudes and opinions of their children, their healthcare professionals, or both. Couples, she found, sometimes experienced difficulty locating an appropriate facility, because many formal residential care settings have generally were not designed to accommodate couples. She also noted that spouses often had dissimilar experiences related to their varying disabilities and health conditions.

Kane and colleagues (2007) suggest that decision-making for moves to formal residential care facilities is particularly challenging because most individuals are relatively inexperienced at it. They note that decision-making frequently occurs when families are stressed and in a state of chaos causing them to experience decision-making in circumstances involving “often-unresolved feelings and conflicts” (p. 247). Their review of the “Long-Term Care Choices tool”, designed by the “Minnesota Board on Aging”, discusses how caregivers using this format first establish the kind of LTC most suitable for the circumstances then determine what sources exist for addressing them (p. 244).

Yaffe and colleagues (2002) conducted a prospective study of “long-term placement” over a five-year period between the years 1989 and 1994 to investigate factors related to LTC moves to NHs beyond the basis of disease progression alone (p. 2090). They followed 5,788 people living in the community with late stage dementia. Participants were drawn from enrollees of the “Medicare Alzheimer’s Disease Demonstration and Evaluation” project of care recipients and informal care provider dyads (p. 2091). Study methods included the use of interviews and multiple instruments to assess care-receiver ADL limitations and “comorbidities,” levels of cognitive impairment, care providers’ ADL or IADL limitations and instances of depression and levels of “caregiver burden,” along with demographic information (p. 2092).

Though Yaffe and associates (2002) acknowledge that decision-making for LTC is a complicated process for reasons intimately connected to both caregiver and care-receiver, they maintain that this investigation helped establish that decisions for moves and their timing are related to “social circumstances, preferences, and values” (p. 2095). Care recipients were more likely to move from the home to NH when caregivers were of advanced years, had a spouse, were engaged in carework for a minimum of “90 hours a week,” were “functionally dependent,” and had a minimum of “6 depressive symptoms” along with a “higher burden score” (p. 2093). The study also found that the influence of the dyad’s characteristics as a team were more predictive of NH placement than the individual characteristics of either the care-receiver or informal care provider alone, emphasizing the importance of the dyad as “a unit” (p. 2095). For those caregivers whose yearly incomes were under \$10,000 or for those who were cared for by a daughter or daughter-in-law, however, moves to LTC were not as probable. Neither were moves to NHs as likely for “elderly black individuals with all ranges of cognitive status compared with elderly white individuals” (p. 2095). Yaffe and associates’ study illustrates how

factors of relationship type and socio economic status, independently or together, may interact to influence moves of individuals with a dementia from their homes in the community to LTC. The researchers also point out that care-receiver/caregiver units who are at risk of dissolving due to combined characteristics of cognitive or physical disability, depression, or burden, may benefit from supportive “services or interventions aimed at delaying” LTC use (p. 2095).

Winslow and Flaskerud (2009) also approached the use of formal residential LTC by investigating perspectives of ethnicity and culture to learn if minorities’ use of LTC differs from that of white informal care providers, agreeing with Yaffe and associates (2002) that race and ethnicity are factors in LTC placement. Settings for LTC were not described or defined in this study (Winslow, & Flaskerud, 2009). The longitudinal mixed methods investigation of 46 informal care providers of individuals with dementia, 12 of whom were described as “ethnically and racially diverse family caregivers,” provided insights into decision-making for moves to LTC (Winslow, & Flaskerud, 2009, p. 197). “African-American,” “Hispanic/Latino,” and “Middle Eastern” participants provided several key concepts relevant to decision-making (Winslow, & Flaskerud, 2009, p. 197.) An African-American daughter expressed that placing her mother in a LTC facility was culturally unacceptable (Winslow, & Flaskerud, 2009). Moreover, pressure from professional advisors to make decisions for moves to LTC was acknowledged by African-American care providers to be an insensitive disregard of their general feelings about relinquishing care to a formal care environment (Winslow, & Flaskerud, 2009). A Middle-Eastern participant expressed that use of formal care settings, rather than family care, was “a shame to the family” (Winslow, & Flaskerud, 2009, p. 197). A Latina care provider noted that informal care provision was not a “choice,” but a cultural way of life (Winslow, & Flaskerud, 2009, p. 198). Other findings included participants’ anxiety over cultural prejudice

that care-receivers might experience as a result of moves to LTC facilities, such as those associated with diet or use of cultural-specific therapies, religious expression, or conflicts with culturally different or culturally insensitive formal care providers (Winslow, & Flaskerud, 2009). Both Winslow and Flaskerud (2009) and Yaffe and associates (2002) agree that elements related to caregiving, such as an availability of caregivers for care recipients and an ability of caregivers to provide care, create unique and individual, if not unpredictable circumstances that may confound study expectations and findings.

Spitznagel and associates (2006) explored factors that predict caregivers of persons with a dementia will make decisions for moves to LTC in a study of 72 participants. Using the “Desire to Institutionalize Scale” and other instruments to assess issues of “burden, dementia knowledge, self-efficacy, depression, health, care recipient daily functioning and memory/behavior problems, family function, and social support,” caregivers of persons with a dementia were found to have markedly more levels of burden and family dysfunction, as well as higher degrees of knowledge, while also having less social support than caregivers of individuals without a dementia (p. 16). The researchers surmise that informal care providers with more dementia knowledge might be more receptive to seeking LTC. Young or single informal care providers were found to be more receptive to institutionalization of their cognitively impaired care recipients, supporting the concept that the type of relationship between an informal care provider and care recipient is related to institutionalization. Other factors, including care providers’ physical or “mental health,” opposition to care recipient behaviors, or levels of care recipients’ cognitive impairment were not found to be influential in decisions for moves for institutionalization (p. 19).

Kelsey and associates (2010) analyzed moves from care recipients' own residences "to ALFs and MCUs from the perspective of family caregivers" (p. 255). The 15 informal family caregivers interviewed in this study using Grounded Theory methods believed that care recipients' moves to memory care benefitted the family. Where differences occurred, however, was among different relationship types of family caregivers. Among caregiving spouses, the researchers found that moves between the home and ALFs to be more challenging than transfers from ALFs to MCUs. For caregiving offspring of care recipient parents, the opposite effect was experienced as moves to ALFs were less difficult and transfers from ALFs to MCUs were more so making moves from the home directly to MCUs more traumatic for caregiving offspring than for caregiving spouses. Kelsey and associates describe this as a "degree of trauma" that is found on a range of experiences associated with moves and related decision-making (p. 261). An additional finding is that of caregivers desire for more information about how AD and related dementias progress, similar to an earlier (2008) finding of Kelsey and associates' regarding administrators, as well as Armstrong's (2000) study of caregiving offspring and spouses.

Resident transitions examined in a study of ALFs where moves were made to MCUs, provided valuable perspectives of administrators' experiences in three setting types: stand-alone ALFs, AL communities with MCUs, and CCRC communities with MCUs (Kelsey, Laditka, & Laditka, 2009). By focusing on the inherent structural influences of the varying settings, the researchers observed how the processes of transitioning residents into memory care differed among them. Information was gathered from 483 ALF settings in South Carolina and included interviews of 31 "executive directors," 1 "director of nursing," 2 "life services" directors, and 3 "residential care" directors (p. 196). In nearly 50 percent of the settings no formalized policy for transferring residents into memory care was found to be utilized. Of those with formalized

transfer policies, most revealed that they did not provide written policy statements during earlier AL setting “admission” processes (pp. 196-197). The study found four main “triggers” initiated transfers into memory care: “wandering or elopement,” “behavioral and safety issues,” escalating “care needs” and “difficulty socializing” (pp. 196-197). The variety of processes for transfers included consultations with family, healthcare providers, and site team members, as well as assessments of residents through both casual observations and interactions, in some cases, formalized protocols.

A study piloted by Kelsey and colleagues (2008) in preparation for their larger (2009) study, examined transitions of individuals with dementia from ALFs to MCUs, relying upon “in-depth telephone” surveys and questionnaires from 10 South Carolina AL administrators (p. 356). Grounded Theory concepts were applied to analyze data for significant “themes.” Similar to the subsequent (2009) study, the researchers found that key concepts exist among administrators for assessing the need for memory care at the time of admission and that different approaches with these concepts are taken. Almost all administrators assessed new residents cognitively, though in only one setting was a standard “tool” used (p. 357). Some administrators addressed the need for memory care services earlier, at time of admission, while other administrators favored delaying decisions until after residents had been medically evaluated. Almost all ALFs in the pilot study were found to have protocols for transfers to memory care; however, a third of participating administrators chose not to discuss these with families at the time of admission. As with the subsequent (2009) study, common “triggers” for transfer included “wandering,” concerns for “personal safety,” problems related to behavior and accelerated “care needs,” and issues related to “socialization” (pp. 358, 359). Decisions for making moves to memory care also varied according to setting type with ALFs in CCRCs tending to rely upon a formalized

interdisciplinary approach and stand-alone ALFs and ALFs with associated MCUs relying upon varying combinations of professional medical evaluations, staff-recommended transitions, and family involvement. Problems during transitions to memory care were noted by a number of administrators and included “family resistance”, including denial of “cognitive” dysfunction, and financial concerns about the more expensive MCU setting (p. 360). At the same time, many administrators suggested that use of “educational materials or opportunities” would be helpful in the transition process between ALF and MCU settings (p. 360).

Mead and colleagues’ study (2005) provides additional views of processes for making decisions to retain or transfer residents with a dementia. By participating and observing in three AL facilities (each with MCUs), as well as engaging in “ethnographic interviews” of 42 participants, equally divided among the 3 sites, the researchers were able to explore the subjective application of facility policies in regard to retaining or transferring residents with a dementia (p. 116). Findings reveal that though “strict, unyielding decision-making criteria existed,” policies were inconsistently followed (p. 117). Although the texts of policies addressed common issues related to dementia decline, behavior, and care, policy adherence was found to be “individually applied” and exact patterns for application of policies were not found (p. 117). Experiences among informal care providers as well as the “facility culture” of the sites impacted the “decision-making processes” for moves to memory care (p. 120). Four common “themes” emerged in regard to transitioning residents with a dementia: management influence, level of care or instances of “problematic or inappropriate behaviors,” degree of family involvement with facility and support of resident, and degree to which a facility was willing to accommodate dementia-related traits of resident (pp. 118-119). A “human component” was the thread linking each of the themes, tipping the balance of not only whether residents were retained in AL,

transferred to MCUs or discharged completely, or moreover, whether they were even accepted as residents in the first place (p. 121). In all facilities, however, though others were stake holders, administrators were the power brokers who interpreted and implemented admission, relocation, and discharge policies for residents with a dementia.

The process of decision-making for moves to formal residential care is generally fraught with difficulty and dependent upon numerous factors. A subset of these decisions, related to moves to memory care, is understudied and demands further exploration. The growing number of aging adults and the particular complexities related to the escalating care needs of elders with a dementia, make the study topic valuable and its timing relevant. Information regarding the decision-making processes of primary caregivers may help expand the literature and provide relevant information for program and service leaders, as well as policy-makers and others whose work has the potential to influence quality of life issues for caregivers of persons with a dementia and their care recipients.

### *Conceptual Model*

Patton (2002) elaborates on the usefulness of social constructionism for maintaining an awareness of the context of participants' experiences and for guiding researchers in capturing the meaning. In the present study, participants' experiences with decision-making for their care recipients' moves to MCUs were shaped and given meaning not only by the contexts of their familial relations to their care recipients' but to a host of other factors, including but not limited to gender, race, and socio economic status. As the theoretical foundation for this project, social constructionism assisted in recognizing individual participants' context of experience.

A social-ecological model acknowledges connections between realms of influence or factors related to phenomena. Where social constructionism theory helps in recognizing

contexts, a social-ecological model helps in explaining relationships between them. In this study, the social-ecological model assisted in understanding how factors of individual-, facility-, and community-levels relate one to the other.

### *Research Aims and Questions*

The literature review stresses the serious and growing issue of dementia in the older population and the simultaneous and challenging need for dementia care options. The principal goal of this study is to understand the decision-making processes of primary informal caregivers in regard to their care-recipients' moves to MCUs. Acquiring an understanding of these experiences is essential to supporting and improving quality of life issues of individuals involved in issues of dementia care. By focusing on informal primary caregivers' decision-making for moves of their care recipients to formal memory care, this study was designed to:

- 1) Advance an understanding of how primary informal caregivers of persons with a dementia make decisions to move their care recipients to MCUs by asking:
  - A. Who was involved in this process?
  - B. What were the various viewpoints of those individuals?
  - C. When were these decisions being made during the caregiving career?
  - D. What locations were considered for memory care?
  - E. Why were decisions for memory care as a LTC option being made?
- 2) Identify individual, facility, and community-level factors that influence decision-making, including:
  - A. What individual factors (e.g., sociodemographic, health characteristics, and living situation of the care recipient and the caregiver) influenced decision-making?

- B. Who were the network support members (e.g., family, friends, faith leaders, professionals) and what are the network support factors that influence decision-making?
- C. What facility-level factors (e.g., fees, size, location, staffing) influenced decision-making?
- D. What community-level factors (e.g., AL regulation, reimbursement policies, and availability) influenced decision-making?

## CHAPTER 2

### Research Methods

#### *Role of the Researcher*

Interest and inspiration for this topic of study and research were drawn from multiple experiences with acquired cognitive impairment in adult family members. These impairments include older-onset Alzheimer's disease (AD); younger-onset AD in Down syndrome; Mild Cognitive Impairment; and the subsequent development of cognitive impairment of two relatives, one following initial recovery from strokes, and the other from a traumatic brain injury.

While these past experiences and connections served to fuel the dynamism of the investigation, they also presented a challenge to focus the research entirely on the strengths of the data presented by participant interviews. To meet this challenge, additional measures were introduced. Journaling commenced prior to the start of research and coincided with participant interviews. It continued through analysis to provide an outlet for personal reflection. I strove for an awareness of potential bias in my choice of probes and how they were introduced during participant interviews and created briefly-worded notes for use with the interview guide. During the analytical phase when data was being interpreted, I relied on the framework of the research aims and study questions to help guide my focus.

#### *Study Approach*

##### *Qualitative Research*

The present study was created in a qualitative design to gather data originating in the individual perspectives of primary informal caregivers regarding how they made decisions for their care recipients' moves to memory care. This approach allowed for interpretation of phenomena, specifically how decision-making was achieved and the related factors, through a

“process” of data collection and analysis that has been described as both “art” and “science” (Corbin & Strauss, 2008, p. 47). The element of art “promotes understanding and increases professional knowledge” and the application of science is rooted in the methods applied to the process of in steps taken for data collection and analysis (Corbin & Strauss, 2008, p. 48). In the present study, grounded theory methods were applied in the qualitative approach to examine the data and work toward the overall goal of the project, that is, an interpretation of primary informal caregivers’ process for decision-making for memory care and related factors.

### ***Grounded Theory Methods***

Formulated in 1967 by Glaser and Strauss, grounded theory is a qualitative method for collecting and examining data in a systematic manner to discover theory as it emerges from the data itself (Corbin & Strauss, 2008). Charmaz (2006) describes this as a “process” of “unfolding temporal sequences that may have identifiable markers with clear beginnings and endings and benchmarks in between” (p. 10). Though she maintains that theory is “constructed” (p. 10) from data, as the researcher’s lens informs the analytic process, she upholds Glaser and Strauss’ foundation that theory is “grounded in the data” (Charmaz, 2006, p. 2).

The heritage of grounded theory includes “symbolic interactionism, a theoretical perspective that assumes society, reality, and self are constructed through interaction and thus rely on language and communication” (Charmaz, 2006, p. 7). According to Patton (2002) symbolic interactionism stresses the significance of “shared meanings” that become “reality” (p. 112). Through the use of grounded theory methods, the shared meanings that emerged from the data drawn from participant caregivers’ interviews helped to construct the resulting theory relevant to the findings detailed in a later section.

### *Selection of Study Sites*

I selected two study sites in the greater metropolitan Atlanta area, both of which offer separate secured MCUs. Administrators from both sites granted access to their facilities to collect data and agreed to facilitate access to potential interview participants for individual face-to-face confidential guided recorded interviews.

While both of these sites were convenience samples, they were also purposively chosen and representative of two different types of LTC settings. Each setting is subject to different state regulatory requirements. The two sites also vary according to size, age, environment, costs and types of payment accepted, as well as residents' race, ethnicity, social status, income, and ability to pay. One site, a NH, is a decades-old facility for which fully one-third of its residents are minorities of multiple countries and ethnic origin. In addition, approximately 80 percent of the NH residents are Medicaid beneficiaries and an unspecified number receive Veterans benefits as well, according to the administrator. The other site, a relatively newly-constructed ALF, has no minority residents and primarily accepts private payment but no Medicaid or Veterans benefits. Both sites are for-profit, corporately owned, and accept LTC insurance benefits. Drawing participants from these two divergent sample sites may provide insights into aspects of decision-making for moves to memory care that illuminate correlations to race, ethnicity, and socio economic factors.

### *Data Collection Methods*

#### *Participant Selection*

Immediately following IRB approval, visits to both study sites' memory care units commenced. Administrators advised me about the days and times MCU family members were most likely to visit. They also provided introductions to staffs to validate my presence and

provide me the opportunity to answer questions. This first step was a crucial to the process for several reasons. I would be coming and going in the study site MCUs for an undetermined number of weeks and my visits needed to be accepted as part of normal daily occurrences. By providing staff members opportunities to meet me, not only was I able to seek staff suggestions for meeting family members and interacting with residents, I was able to establish professional relationships that would allow them to understand my role in their work environment and partner in the research process by assisting with introductions to potential participants. Staff support proved to be invaluable. At both study sites, staff openly conveyed acceptance of me and the project helping curious and sometimes hesitant family members to develop an interest, if not a desire to participate in the study project.

Both administrators allowed me to post an approved study announcement for campus visitors. At the ALF, I was required to provide the administrator a copy of the light blue colored announcement in a simple black frame which was placed in the ALF's front entry on the center foyer table next to a vase of fresh flowers. For the NH, I was told I could tape copies of the announcement where I thought potential participants might see them. I chose to laminate two copies of the light blue colored announcement and hung one over the MCU entry keypad outside the unit. The other was hung over the MCU's exit keypad just inside the unit. In addition to the posted announcements, copies were made and supplied to unit supervisors and staff. I also carried copies in a tote which accompanied me daily to each site so that I could provide potential participants a copy as needed.

To meet family members for the purpose of scheduling participant interviews, I visited the two study sites over a course of twenty-one straight days. Each day I wore a Georgia State University name tag with my name clearly visible and professional clothing appropriate to the

work culture of the site visited. The ALF site was less casual than the NH site. Beginning with visits to the ALF site, then gradually adding visits to the NH site, I began to schedule study participants for interviews. Each study site visit lasted approximately two hours. During this time I interacted with residents in conversation and activities and met their families. My goal was to blend in with the lifestyle of each site, presenting myself as friendly, approachable, and available. Spending time visiting with MCU residents was an activity that I greatly enjoyed on its own merits. These visits became a type of valuable currency when meeting and talking with family members to introduce the project and seek their participation because they had had the opportunity to informally observe me in their family members' environments. During visits, family members, residents, and staff members readily engaged me in conversation providing a strong introduction to the study MCU settings from their perspectives. In the beginning, administrators and staff at each site facilitated some initial introductions to potential participants, but after a time, I made my own introductions and family members began to seek me out.

Administrators were provided criteria for identifying potential participants, that is, those family members of memory care residents who were most active and instrumental in the care and decision-making processes of those residents. Additional criteria included participants who varied by gender, ethnicity, and generation as much as possible, as well as varying by family relation as much as possible, e.g. spouse, adult child or spouse of adult child, niece, nephew, etc. Residents of memory care were not asked to participate.

### ***Guided Interviews***

Potential participants were provided general information about the purpose of the study. Those who were interested in participating were asked to consent to individual confidential guided face-to-face recorded interviews, proposed as lasting about 1.5 hours in duration.

Selected participants were encouraged to choose the time and place of the interview, but all chose to participate at the study site of their recipient.

To prepare for upcoming interviews, I sought the advice of the study site administrators for private on-site locations that could be used for interviews. The ALF made available two comfortable and professionally decorated rooms, a small second-floor theatre room and the first floor private dining room, both with thick carpeting and overstuffed upholstered chairs, and soft lighting. Both also had doors which allowed them to be closed off from the ALF's public halls. I merely needed to reserve these rooms in advance with the receptionist as needed. When in use for interviews, I posted a small sign, *Reserved for Private Meeting, Thanks*, attached to a plaid ribbon so that it could be hung from the door handle to help ensure we were not disturbed. Three ALF interviews took place in the theatre room. The private dining room was never available as it was often used by AL resident groups for bridge games, knitting groups, or other resident-planned activities. On one occasion, both rooms were unavailable and I used a sitting area located in a private alcove at the end of a long second floor hall unoccupied by residents' rooms. On another occasion, I and the interview participant were asked to relocate because the room had been double-booked. On this day we were taken to a second floor model room that was being used for storage. It was a chilly winter day outside and the heat was turned off in this room. The lighting was harsh and the atmosphere was uncharacteristically inhospitable, but the interview participant wanted to proceed in this location and so we did.

At the NH, I was provided two private rooms with closing doors for interviews as well, and like at the ALF, these rooms were reserved through the receptionist. I continued to use the small sign to ensure privacy. Both rooms were located in the NH's somewhat chilly basement and were constructed of concrete block walls and laminate tile floors. One room was furnished

with a small round table and frame chairs and was used mostly for family care conferences. The other room was a staff training room that smelled slightly of mildew and contained shelves of various types of medical equipment for training exercises, some of which were realistically painted with fake blood. Long plywood tables and metal folding chairs furnished this room. Both rooms contained windows overlooking a park-like and little-used NH courtyard. I purposefully set up NH interviews so that the participants' chairs faced in the direction of the windows and more pleasant view. Two interviews took place in the family care conference room. One interview took place in the staff training room when the family care conference room was unavailable. Two other interviews took place off-site. For one, I met the participant at a coffee house that had a private room I was able to reserve. The other took place in the early evening in a hospital chapel, suggested by the participant, after she completed her workday.

For all interviews, I arrived early to prepare, turning on or adjusting lighting, and setting out two small bottles of water, each on a printed cocktail napkin. To each interview I brought with me one small potted plant to thank participants. This, I placed on a meeting or chair side table with our water, then presented it to the participant at the end of the interview. The plants varied as I typically picked up two or three at a time at a local nursery. Most participants seemed very pleased, if not touched by the gesture, as evidenced by their hugs or tears upon presentation.

***Informed Consent Procedures.*** Each confidential interview began with *Informed Consent* procedures. These entailed an explanation of measures of confidentiality taken during the research process and a brief discussion of participant rights and benefits and potential participant risks. Measures of confidentiality included private storage of study interviews and materials, as well as no use of identifying names of people, agencies, facilities, or locations, with aliases substituted for all as transcripts were typed. The only identifying name used was

metropolitan Atlanta to describe the study location. Participant rights included the right to skip questions, stop the interview at any time and ask for referral to professional counseling for experiences of emotional upset. Participant benefits included the opportunity to talk about decision-making and related experiences which possibly would aid professionals assisting future caregivers in similar circumstances. Potential participant risks covered the possibility of emotional upset. Following questions and answers about any aspect of the informed consent document, the participant's signature was obtained on one of two copies of the *Informed Consent*. I retained the participant-signed copy for record-keeping purposes and signed the second copy for the participant to keep. A complete copy of the *Informed Consent* is found in Appendix A.

***Demographic Questions.*** Following *Informed Consent* procedures, each participant was led next in a brief face-to-face unrecorded demographic survey of closed questions to establish among other factors, age, gender, race, and education of both the primary caregiver and his or her recipient. These questions helped to understand and later describe individual participants' characteristics. A complete copy of the *Demographic Questions* is found in Appendix B.

***Guided Recorded Interviews.*** Participants who consented to being recorded were led through a series of conversational-style open questions in face-to-face guided recorded interviews. All participants agreed to recorded interviews.

Interview questions were grouped into the following main categories: *Personal History of Caregiver*, *Personal History of Care Recipient*, *Caregiver/Care Recipient Relationship*, *Dementia History*, *Dementia Knowledge*, and *The Decision to Move to Memory Care*. Participants were led through two final sections, *Opportunity for Caregiver to Advise* and *Closing Questions* to encourage caregivers to talk about matters for which earlier probing

questions may not have provided the opportunity to express thoughts or experiences. All interview questions were accompanied by brief researcher notes (probes) to assist me in guiding the conversational-style interview along the research study aims. A complete copy of the *Guided Interview* is found in Appendix C. Each interview was transcribed by me on the day of the interview shortly after concluding.

### *Data Analysis*

Data analysis was conducted according to the qualitative approach of grounded theory methods. Each interview was transcribed and typed word for word by me on the same day it was recorded. Beginning with the first transcript, each transcribed interview was analyzed line-by-line for meaning and concepts described as initial coding, according to the process described by Charmaz (2006). An example of initial codes from the transcripts included the words *tiring*, *accept*, and *wandering*, among others. Memoing was added to the process to help “develop” the thought process of codes’ meanings (Charmaz, 2006, p. 11). Memoing continued throughout the analytic process. Initial codes were then scrutinized and grouped into categories according to similarities according to a process of comparison (Charmaz, 2006, 54; Corbin & Strauss, 2008, 73). Categories from the present study’s analysis include *caregiver burden*, *caregiver feelings*, and *care recipient behaviors*, among many others. As each new interview was transcribed, the process of initial coding and categorization continued between them.

Another type of code also emerged from the transcripts, “in vivo codes” (Charmaz, 2006, p. 55). These have been described as “symbolic markers of participants’ speech and meaning” (p. 55). In vivo codes may be commonly known expressions, or new expressions unique to participants, or “insider shorthand”, all of which imply particular meanings for individual

participants p. 55). Emerging in vivo codes include *there are worse things than death* and *I just feel like I've thrown him away*.

The continued coding process led to “axial coding” by which earlier categories were linked with sub-categories establishing “how” categories were related (Charmaz, 2006, p. 61).

A large number of charts were created to assist in the process of separating, listing, and categorizing data. First, I created a standard set of charts for each of the ten interviews to separate and record data according to *Prior Living/Care Situation, Making Decision to Move to MCU – Precipitating Events & Those Involved, Making Decision to Move to MCU – Influential Factors & Outcomes, and Site Selection*. The creation of other charts soon followed to examine the caregiving experience according to *Individual Caregiver Factors, Individual Care Recipient Factors, Living Arrangement & Care Utilization, Paths to MCU, and Caregiver Outcomes*, among many others. The charts not only proved to be essential during the analytical process, but quite useful as templates for creating the tables included in this study's subsequent chapters.

I also began to form theories about how the process of decision-making for moves to memory care was viewed by participants, including who was involved, at what point in the caregiving careers decisions were made, what locations were considered for memory care and why decisions for long-term memory care were made. Individual-, facility-, and community-level factors related to the individual perspectives also began to emerge. These conclusions laid the groundwork for the study's findings that are discussed in detail in subsequent chapters.

## CHAPTER 3

### DESCRIPTIONS OF STUDY SITES

This chapter describes the two study sites including 1) a description of the surrounding area of the study sites, types of payment accepted, and services provided, 2) costs, 3) facility setting, 4) general facility setting, 5) MCU setting, Each study site description includes information about the facility's surroundings, types of payment accepted and services provided, costs, general facility setting, MCU setting, 6) census and description of residents, councils and community engagement, and administration.

#### *Smithville Retirement Home and Nursing Care*

##### *Surrounds, Types of Payment Accepted, and Services Provided*

Smithville Retirement Home and Nursing Care (RHNC), located in an older urban residential and light commercial area, has served its community since the early 1950s. A for-profit facility, it is currently licensed for 268 total beds, 51 of which are located in its MCU known as Heritage Hall. The property is owned and managed by an out-of-state corporation that owns and operates similar retirement and nursing care facilities in nine other Georgia locations and six other states. It accepts Medicare, Medicaid, LTC and Veterans benefits, and private pay. Smithfield provides long-term skilled nursing care, including IV infusions, tube feedings, and wound care, as well as short-stay rehabilitative and respite care. Eligible residents may also receive in-house hospice services. On-site physical, occupational, and speech therapies can be provided to residents, as well as to short-stay in-patient and out-patient clients. No adult day program services are offered.

### *Fees*

Private pay rates at Smithville RHNC as of September 1, 2010 are quoted as daily room rates. A private room costs \$195 a day, a semi-private unit is \$185 daily, and a “three-bed suite” costs \$180 day. Medicaid rates are based upon a private room allowance of \$175.62 daily. Residents who receive Medicaid assignment may opt to private pay the daily difference to maintain residency in a private room. There is no difference in the daily rates charged to residents living in the general population versus those residing in Heritage Hall. Nor is there any difference in the rates charged to those who are short-term residents, including those who are receiving respite services. Short-term and respite services are offered for beds in both the main level and in Heritage Hall on a minimum cost basis of 7 days, however. Approximately 80 percent of residents utilize Medicaid for payment of services.

### *General Facility Setting*

Renovations in the late 1970s added significantly to property’s physical building, a rambling single-story brick and concrete block structure consisting of a main level and a daylight lower level. In addition to a large covered front porch, furnished with cushioned rocking chairs, partially shaded by mature trees, and landscaped with seasonal flowers and a variety of shrubs, the facility has two self-enclosed shaded courtyards with benches. One courtyard is located off a main level nursing hall and offers a partially covered terrace. The other courtyard is accessed from the lower level for the exclusive use by Heritage Hall residents as scheduled activities allow. A small sitting area is provided just inside the NH’s main doors and two other similarly-sized areas are located where perpendicular halls meet. One sitting area contains a television and a computer for residents’ use. The other is furnished with a small bookcase and electric fireplace. The dining hall, centrally-situated to most residents’ rooms, doubles as an activity

room and is furnished with stereo equipment. All exits are controlled, including those to the self-enclosed courtyards. The property utilizes the *Wander Guard* alarm system for all stairs, elevators, and exterior entrances and exits.

### ***Memory Care Unit Setting***

The administrator states that Smithville RHNC has always maintained a secured section within the general facility, noting that it was primarily utilized as a “psych unit” for “behavioral problems” in the facility’s earlier years. It is not known at what point Heritage Hall became formally recognized as the MCU, though according to the administrator, it has been so designated since at least late in 2004. The unit is entered or exited by use of a keypad code at the entrance and exit doors.

Heritage Hall consists of a long dog-leg shaped unit with resident rooms, a small dining room for higher functioning residents and a television room located along either side of a central hall that ends in a larger day room that doubles as a dining room for residents requiring assistance with meals. A nurses’ station is positioned in the turn halfway down the hall. Natural daylight comes into rooms through small windows. The unit’s central hall is lit by overhead fluorescent lighting.

### ***Census and Description of Residents***

According to a September, 2010 census, 136 residents and short-stay clients are presently housed in double and triple- occupancy rooms. The lower level is utilized for rehabilitation services, business and support services, and is where Heritage Hall’s 45 memory care residents are located, housed mostly in triple-occupancy rooms, though a few reside in semi-private units.

Smithville RHNC’s annual facility census noted that as of March, 2010, there are 39 African-American, 8 Asian (primarily Korean, Vietnamese, and Filipino), 5 Hispanic, and 120

Caucasian residents. A significant but unspecified Russian immigrant population is counted among Caucasian residents. According to the administrator, Russian residents are drawn to the RHNC because of a well-respected Russian employee of high standing in a Russian immigrant community in metropolitan Atlanta.

Overall, approximately 93 percent of all residents are aged 65 and older. The youngest person residing at the Smithville facility, however, is 28 years. Table 3.1 shows the number of residents on property according to specific age categories of adults age 65 and older.

**Table 3.1 Smithville RHNC September 2010 Census**

<b>Age</b>	<b>Total Number of Male Residents on Property</b>	<b>Total Number of Female Residents on Property</b>
65-74	9	27
75-84	17	39
85+	8	46

According to the administrator, a “few” married couples reside on the main level in the general population of Smithville. However, no individuals who reside in Heritage Hall have a spouse who also resides in Heritage Hall or in the general population. Of spouses of Smithville RHNC residents, “a couple of [spouses] come regularly” to visit their general population spouses and “a good share” of those with a spouse in Heritage Hall come often to visit that spouse, notes the administrator.

### ***Councils and Community Engagement***

Main level residents of the general population may participate in a monthly resident council and make recommendations to the administration. Grievances are typically handled through the site's social services office. Families of Heritage Hall residents may attend quarterly family meetings facilitated by the administrator. These meetings are usually educational in nature and often feature guest speakers.

A volunteer corps is maintained through the Activities' Department. Faith communities and civic organizations, as well as individuals, routinely provide entertainment and one-on-one visits throughout the facility, according to the administrator. Heritage Hall residents also regularly participate in activities coordinated or facilitated by the Activities Director on the main level as considered appropriate and as long as sufficient supervision is available. The facility is currently raising money to purchase a van for off-site activities and general transportation.

### ***Administration***

Smithville RHNC's administrator has held this position since 2004 and has a bachelor degree. Heritage Hall's clinical supervisor and unit manager is a Licensed Practical Nurse (LPN). The property's Activity Director holds a master's degree and Heritage Hall's activity leader has a bachelor degree.

### ***Meadow Manor***

#### ***Surrounds, Types of Payment Accepted, and Types of Services Provided***

Meadow Manor is a relatively new for-profit AL property offering secured memory care. Opened in 2010, it provides 93 units licensed for 115 individuals, of which 26 units and 39 residents are housed in the Cottage MCU. All property units are either single or double occupancy. Situated in a suburban established residential and light commercial area, Meadow

Manor is owned and operated by its founding corporation. Corporate offices and five similar combination AL and MCU properties are all located within the state of Georgia. Additional sites are owned or managed in six other states. All property locations offer AL and memory care, with the exception of one location that offers independent and AL. Meadow Manor is a private pay facility where LTC insurance benefits are accepted but no application to accept Veterans Administration benefits has been made.

Though skilled nursing is not offered, three levels of supportive care for those who require increasing assistance for activities of daily living (ADLs) are. Medication management, including diabetic medication care, is available. Additionally, Meadow Manor offers on-site physical, occupational, and speech therapy services provided through contracted providers. Other available services include overnight respite care in both assisted living and memory care sections, as individual room openings allow. Adult day program services are not currently available, though in the past, census openings in the MCU did allow for the provision of these services.

### ***Fees***

Private pay monthly base rates for assisted living at Meadow Manor, as of September, 2010, begin at \$2,294 and top out at \$4,495, depending on the square footage and aesthetic location of the unit, and whether the unit is shared. For Cottage residents, monthly base rates begin at \$3,795 and rise to a maximum of \$5,995. As stated for AL residents, rates are assessed according to square footage and aesthetic location of the unit and if the unit is shared with another person. A deposit equal to one month's rent is also charged to all new residents.

Additional monthly fees are assessed according to three different levels of care. These fees begin at \$450 a month, rise to \$700 a month, and max out at \$1,400 a month. Other

monthly fees, if not already included in one of the three assisted living levels of care, are \$1,200 for a related co-resident in the same unit; medication management \$300; diabetic medication management \$200; personal laundry service for \$150; furniture rental, beginning at \$200; the one-time fee for a pet, \$300; and the one-time fee for a call-assistance pendant \$150. Respite care begins at \$150 a day for a stay in assisted living and \$200 a day for memory care.

### ***Assisted Living Setting***

Meadow Manor's physical structure is a single two-story brick and siding building of 75,000 square feet set on approximately 7 acres of custom landscaping and floral gardens. The covered front entry is flanked by covered porches with tables and chairs. Adjacent to the foyer are two comfortable sitting areas, one with a fireplace and bookcases. A café, kept furnished with fruit, drinks, and other snacks, is located beyond one well-appointed sitting area and opens to another covered porch and outdoor sitting area facing a garden, lawn, and walkway for strolling. The property's main dining room is located near the foyer and contains tables set for foursomes and a grand player piano. Natural light from large windows flood the first floor public spaces. Just beyond the foyer are administrative offices, first floor residents' units, and entry to the Cottage. A wide staircase and elevators provide access to the second story of the property.

The second story contains additional assisted living residents' units, a large activity room furnished with several computers for residents' use and a guest kitchen, a landing sitting area, a nearby den with multi-media equipment, the clinical care and records station, and therapeutic rooms.

### ***Memory Care Unit Setting***

The Cottage, entered and exited by use of a keypad code, consists of an open living room with media equipment and dining areas adjacent to a central foyer. A studio piano is also located here. A climate-controlled all-weather sun porch, accessed through double doors in the central foyer, leads to an enclosed garden with a circular paved garden path. The garden area is furnished with umbrella tables and chairs and benches. Daily access to the garden is provided and encouraged as weather allows. Residents' rooms are located in two halls, each of which lead from the central foyer. Near the central foyer is a clinical care and records station, a guest kitchen, used daily to serve meals and snacks, and the Cottage administrator's office. Natural light floods the MCU public areas and residents' rooms.

### ***Census and Description of Residents***

The current property census includes 64 assisted living residents and 38 memory care residents. All are Caucasian and most reside individually in single occupancy rooms. According to an administrator, there are 3 "international" residents at Meadow Manor, two from Germany and one from Austria.

Table 3.2 provides facility census information as of February, 2011. Of the 64 AL residents, 29 are male and 35 are female. In the Cottage are 14 male residents and 24 female residents. Two married couples reside in the Cottage, as do 9 married couples in AL units. One other married couple lives at Meadow Manor, with one spouse residing in AL and the other spouse living in the Cottage. Eight other Cottage spouses have partners residing outside of Meadow Manor. Five AL spouses have partners living off property.

**Table 3.2 Meadow Manor February 2011 Census**

<b>Area of Residency</b>	<b>Number of Male Residents</b>	<b>Number of Female Residents</b>
<b>AL</b>	29	35
<b>MCU</b>	14	24

***Councils and Community Engagement***

A monthly residents' council is available for all AL residents and a quarterly family council meets for residents of the Cottage. One administrator attends each resident council meeting, but all managers meet with Cottage residents' families at their quarterly gathering. None of the Cottage residents attend the quarterly meeting. In addition, an Alzheimer's support group regularly meets on the property.

Individual volunteers and members of civic organizations and faith communities routinely provide additional activities for residents in assisted living or in the Cottage. A property van is available for all residents' off-site routine community rides, activities, and transportation.

***Administration***

The property administrator holds a master degree, as well as a Registered Nurse (RN) license. The Cottage manager holds a bachelor degree and an LPN license. The Activities Director has a master's degree. Table 3.3 shows the summary of main characteristics of the two study sites for comparison.

**Table 3.3 Summary of Study Sites' Characteristics**

	<b>Smithville RHNC</b>	<b>Meadow Manor</b>
<b>Site Type</b>	Skilled Nursing & Rehabilitation Secured Memory Care	Assisted Living Secured Memory Care
<b>Ownership</b>	Corporate-owned, For-profit	Corporate-owned, For-profit
<b>Facility Age</b>	Built in early 1950s	Built in early 2010
<b>Licensed Facility Capacity MCU Capacity</b>	268 beds 51 beds	93 units/115 residents 26 units/39 residents
<b>Services</b>	Long-term/short-stay skilled nursing & rehabilitation; in-house in-patient/out-patient PT/OT/ST; overnight respite & in-house hospice care	3 ADL care levels; medication management; contractor-provided PT/OT/ST; overnight respite & contractor-provided hospice; adult day program (as openings allow)
<b>Fees</b>	\$195 day - private room \$185 day – semi-private room \$180 day – 3-bed suite (Costs same for all rooms, all stays, unsecured/secured.)  Maximum Medicaid benefit: \$175.62	\$2,294 - \$4,495 month – AL \$3,795 - \$5,995 – MCU + unit deposit = 1 month rent + \$450 - \$1,400 ADL care (Additional fees applicable to individual care situations.) Respite - \$150/day AL; \$200/day MCU
<b>Types of Payment Accepted</b>	Medicare, Medicaid, LTC Insurance & Veterans Benefits, Private Pay	Private Pay, LTC Insurance
<b>Most Frequently Type of Payment Utilized</b>	Medicaid (Approx. 80%)	Private Pay
<b>Resident Description</b>	(Approx.) 66% Caucasian, 20% African-American, 8% Russian Immigrant, 4% Asian, 2% Hispanic	100% Caucasian

## CHAPTER 4

### CHARACTERISTICS AND PROFILES OF PRIMARY INFORMAL CAREGIVERS

This chapter is divided into two main sections: 1) study participants' characteristics and, 2) profiles of each of the study's ten caregiving experiences. Each profile is a snapshot told through the perspective of the primary informal caregiver. Profiles are divided between spousal caregivers and non-spousal caregivers because their experiences are qualitatively different. The profiles describe the primary caregiving and care recipient pairs through a history of their relationship, with details of care-recipients' prior living and caregiving situations including others who have been active in supplementary roles, and when and how the care recipients' moves to memory care occurred. Individual primary informal caregivers' viewpoints of the process of making decisions for care recipients' moves, the timing of those decisions, and the circumstances and reasons for choosing specific memory care locations among available long-term care options are also discussed.

#### *Study Participant Characteristics*

The study's ten caregiving participants include four wives, one husband, four daughters, and one sister. Half of the ten care recipients reside in the AL MCU and the other half reside in the NH MCU.

#### *Spousal Caregivers and Care Recipients*

Five of the ten study participants are spousal caregivers. Table 4.1 summarizes their characteristics. They range in age from 59 to 76 years and have been married an average of 48 years. Four are wives. Two have college degrees and three have high school diplomas or an equivalent thereof. Four are white and one is Black of Caribbean origin.

**Table 4.1 Spousal Caregiver Characteristics**

	<b>Reba Chatham</b>	<b>Annette Harrow</b>	<b>Allene Ballentine</b>	<b>Theo Vance</b>	<b>Sandra Bradley</b>
<b>Age</b>	71	76	64	72	59
<b>Race</b>	White	Caribbean, Black	White	White	White
<b>Education</b>	H.S. Diploma	Certificate of Completion	College Degree	College Degree	H.S. Diploma
<b>Relationship to Care Recipient</b>	Wife	Wife	Wife	Husband	Wife
<b>Years Married to Care Recipient</b>	55	53	41	50	41

Table 4.2 shows the characteristics of spousal care-recipients. They range in age from 61 to 79. Three have college degrees, one has some college, and a fifth as the equivalency of a high school diploma. Two have lived in the AL MCU for one and two years respectively, while residency in the NH MCU for the other three ranges from two days to five years. One, John Harrow, lived in the general NH population prior to the move to the MCU. The other four moved directly from home to the MCU. Diagnoses of spousal care recipients include AD, LBD, and VaD.

**Table 4.2 Spousal Care Recipient Characteristics**

	<b>Roger Chatham</b>	<b>John Harrow</b>	<b>Luke Ballentine</b>	<b>Mary Margaret Vance</b>	<b>Jack Bradley</b>
<b>Age</b>	79	76	67	69	61
<b>Race</b>	White	Caribbean, Black	White	White	White
<b>Education</b>	College Degree	Certificate of Completion	Some College	College Degree	College Degree
<b>Years Married</b>	55	53	41	50	41
<b>Diagnosis</b>	VaD, AD	VaD, AD	LBD	AD	LBD
<b>Apparent Symptom Onset</b>	2003	1996	2008	1994-95	2009
<b>Current MCU Location</b>	AL	NH	AL	NH	NH
<b>Time in Other Residential Settings</b>	NA	NH-1 Year	NA	NA	NA
<b>Year of MCU Placement</b>	2009	2006	2010	2006	2011
<b>Time in MCU</b>	2 Years	5 Years	1 Year	5 Years	2 Days

***Non-Spousal Caregivers and Care Recipients***

Table 4.3 presents the characteristics of the five non-spousal caregivers, which include four daughters and one sister, aged 37 to 66. All five are married and white. Four have college degrees and one has some college. Four are responsible for parents, three for mothers, one for a father, and one cares for a sister.

**Table 4.3 Non-Spousal Caregiver Characteristics**

	<b>Marsha Balfour</b>	<b>Cecelia Beech</b>	<b>Dee Waterhouse</b>	<b>Jilly Thornton</b>	<b>Pamela Hamm</b>
<b>Age</b>	66	51	57	37	66
<b>Race</b>	White	White	White	White	White
<b>Education</b>	Master's Degree	Professional Degree	College Degree	Some College	College Degree, R. N.
<b>Marital Status</b>	Married	Married	Married	Married	Married
<b>Relationship to Care Recipient</b>	Daughter	Daughter	Daughter	Daughter	Sister
<b>Care Recipient MCU Location</b>	AL	AL	AL	NH	NH

Table 4.4 illustrates the characteristics of non-spousal care recipients. They range in age from 68 to 90. Two are widows (one twice), two are divorced, and one has never been married. Two have college degrees and one has an associate degree, one other is an RN, and the fifth has a high school diploma. All are white. Three have lived in the AL MCU for between three months and two years and the other two have lived in the NH MCU for between three months and five months. Diagnoses include AD, Dementia, and VaD.

**Table 4.4 Non-Spousal Care Recipient Characteristics**

	<b>Catherine Dunn</b>	<b>Janet Chester</b>	<b>Fred Grant</b>	<b>Anne Littleton</b>	<b>Theresa Keller</b>
<b>Age</b>	89	85	90	70	68
<b>Race</b>	White	White	White	White	White
<b>Education</b>	Master's Degree	H. S. Diploma	College Degree	R. N.	Associate Degree
<b>Marital Status</b>	Twice Widowed	Widowed	Divorced	Divorced	Never Married
<b>Diagnosis</b>	Organic Brain Syndrome, AD/VaD	VaD, AD	Dementia	AD	Dementia
<b>Apparent Symptom Onset</b>	2005	2006	2007	2003-04	2004
<b>Time Other Residential Setting</b>	IL-5 Years AL-5 Mo.	AL-1 Year	NA	NH-9 Mo. AL-2 Days MCU-4 Mo.	NH-2 Mo.
<b>MCU Location</b>	AL	AL	AL	NH	NH
<b>Time in MCU</b>	3 Months	18 Months	2 Years	3 Months	5 Months

*Profiles of Spousal Informal Caregivers and Their Care Recipients*

*Reba and Roger Chatham*

Reba is a white, 71-year-old homemaker with a high school diploma and three years of religious studies. She first met and became “enamored” of her 79-year-old care recipient husband Roger, a retired businessman, when she was a teenager and he was an 8 and a half years older veteran. Following a brief and intense courtship, Reba’s mother conspired with them so that they could be secretly married by a justice of the peace. Reba remained in her parent’s home to complete high school and Roger left to attend college elsewhere in the state. Upon her graduation, Reba moved from her father’s home and strong patriarchal influence in rural Georgia

to make a home with her husband at his college's married housing development and worked full-time while Roger completed his bachelor degree. Because Roger had similar traits as her father, Reba's lesson of learning not to "rock the boat" with her father helped her learn how to "acquiesce" and "cooperate" with "a domineering and controlling" man.

Though Reba continued to work outside the home for many of her married years, decisions in the home were Roger's domain. She and Roger shared few similarities, but over the years his numerous interests became hers and she willingly complied with his choices and leadership, except for her choice of a faith community separate from Roger's. Reba's strong faith was her private haven and the foundation on which she relied to cope with Roger's ensuring changes and her caregiving role.

Very soon after his retirement in 1997 Roger noticeably began to withdraw from his many pursuits and interests. In 2003 he experienced what Reba believed to be a light stroke, continued a steady one-year decline and later was diagnosed with VaD and AD. For the first time in their marriage Reba stepped into the leadership role, gradually taking over tasks and making decisions. Roger began losing skills such as driving and making simple home repairs such as mending a leaky faucet, lost interest in reading the newspaper, and became unable to manage his medicines and diabetic care routine, pay bills, and mow the grass. Reba began to fear for his safety on his daily walks alone in their neighborhood. She changed the house locks and began supervising him closer. Eventually, Roger began to require assistance with bathing, shaving, and toileting. Roger remained sexually aware and being bathed by Reba and seeing her undress at bedtime stimulated him. Roger's advances felt like "incest" to Reba and she sought outside assistance for his care.

Reba and Roger tried one adult day program that also provided informal caregivers a support group. Reba had few involved friends and little to no support from her children. However, because of the support group's low turn-out, Reba found its negligible benefit was not worth the effort it took to get Roger ready and arrive at the program. Reba next began a trial and error process of finding a home health aide and after two failed attempts found one that was satisfactory.

After six years of caregiving Reba began to tire and question her ability to continue and felt somewhat "trapped." Her doctor was concerned for her health, often reminding her that she would not be able to keep up this same caregiving pace. Her best friend gave her similar advice and urged her to investigate a new ALF that offered memory care. At the other extreme, her children, two of whom live in the local area, questioned Reba's perception of the extent of their Roger's decline and caregiving needs. Reba had read quite a bit about "multi-infarct" (VaD) dementia and gained general knowledge of dementia through a family member and a friend and understood some of what the future might hold for Roger and her. Despite challenging emotional aspects, Reba felt gratified in her role as decision maker for both the home and for Roger. In addition, she felt a deep respect for her marriage vows that necessitated taking good care of her husband. For a brief time, Reba even considered remodeling their home to make it more accommodating to Roger's needs. The sum of these experiences was empowering.

Eventually, Reba decided that for her own and Roger's well-being she could no longer keep Roger at home and investigated the new ALF with memory care and made a deposit. Though the ALF was not close to her home, it was near the home of one of their daughters and to the grandchildren, which comforted Reba. Before Reba had the opportunity to talk to her children about her decision Roger had a crisis at home experiencing a period of

unresponsiveness. When their two local children arrived to assist, Reba told them of her decision and was rewarded with their acceptance and support. Soon afterward, all three children assisted their mother with Roger's move to the Cottage at Meadow Manor where he has lived for just over two years. Today Reba visits Roger in The Cottage about once a week.

### ***Annette and John Harrow***

Seventy-six-year-old Annette and her 81-year-old husband John, natives of Trinidad, West Indies, have been married 54 years. They have two daughters and three sons. One daughter lives in the Atlanta area, one son lives elsewhere in Georgia, and a second son lives in a northern state. Although each has seven siblings, only a brother and sister of John's reside in this country. Both Annette and John have certificates of completion for school through 18 years of age. Annette reluctantly moved to the U. S. with John in 1990 to follow John's brother to a large metropolitan city in the northeast. They both found work at a residential care facility for the mentally disabled. Annette remembers this as a time when they were close and she enjoyed cooking the sweet treats that John loved.

In 1996 John experienced a stroke. At this time he and Annette were living in an apartment in a northeastern state. Annette continued to work sporadically, but John's unpredictable episodes of agitation and frequent roaming caused Annette considerable unease and their lifestyle changed dramatically because of numerous incidents. Though Annette did not understand what was happening to John, she took comfort in her strong faith and strove to "accept" their changed lives. Her marriage vows framed her desire to protect and care for John.

Over a period of years, which included an eight-month return to Trinidad and a six-month stint living with a son in a Midwestern state, followed by a six move into their own apartment, John's erratic behavior and agitation increased, sometimes resulting in Annette calling law

enforcement. John's response to these emergencies included combative behaviors, once assaulting a paramedic, resulting in John's psychiatric hospitalization. During one hospital visit, John hit Annette in the mouth, seemingly in anger which surprised and confused Annette.

By 2003, Annette had stopped working to take care of John full-time. Eventually, they moved to their daughter's home in Metro Atlanta where their daughter was able to provide some support. John could manage all his own personal care, but his elopement behaviors were becoming a greater concern. Their daughter began sleeping on the sofa at night after she pulled it across the door to keep John from leaving. Sometimes, John turned on the lights and packed his clothes.

John's treatment during his escalating decline included shock treatments, hospitalizations, and changed medications, depending on the location of services and the prescribing care provider. Annette continued to occasionally rely upon law enforcement for help when John refused to stay at home. Finally, in 2005 John's physician advised Annette to seek nursing home placement, as John's advancing VaD and AD were becoming unmanageable and Medicaid-eligible facilities were necessary because of their financial status.

Annette learned from a neighbor that Smithville Retirement Home and Nursing Care existed within walking distance of her daughter's home and when a place was available, John moved into the general population of the facility. In 2006, John's frequent elopements caused nursing home administrators to insist that John move to Heritage Hall, the facility's secured MCU, where John has since lived. Annette walks to see John approximately four times a week.

### ***Allene and Luke Ballentine***

Allene, 64 years old and white, has known her husband Luke, aged 67, for 45 years. They have been married 41 of those years in a close and loving relationship that extends beyond

life partners to partners in business. Allene has a bachelor degree while Luke has two years of college. They have two sons, one of whom lives in the local area with his own family that includes two daughters. Their other son is single and lives in a western coastal state.

When not working together, Allene and Luke were constant companions enjoying travel and tennis among other pursuits. Allene admits that she chose activities and interests, with Luke content to follow her lead, noting that she was “his hobby.” In 2003, Luke received the “raw deal” of a Parkinson’s disease (PD) diagnosis. He focused on exercise to combat the disease, engaging a trainer and taking up archery. However, before the end of 2008 Allene began to notice subtle then more disturbing changes in Luke. Luke first seemed to grow less mentally sharp and more reliant on Allene. By December of 2008, Luke had totaled their car and stopped driving altogether. Allene had always managed their financial affairs, but being responsible for Luke was a huge change. She stopped working to provide around-the-clock care, including toileting, showering, and giving medicines. Allene’s social outlets disappeared. After a frightening and acute episode of wildly uncharacteristic behavior, Luke required psychiatric hospitalization. Allene continues to chide herself for not recognizing the meaning of Luke’s behavior given that she had read about PD and LBD as well as had prior family experience with a parent’s dementia. Until Luke’s diagnosis in May of 2009, she dismissed the possibility that dementia was responsible for Luke’s changes. The LBD diagnosis was impossible for Allene to ignore, however, because a condition of Luke’s hospital discharge was for Allene to consent to Luke’s placement in a daily “structured environment” of her choice.

Allene researched facilities near her home, visiting three different properties and decided to enroll Luke as a day-only participant in Meadow Manor’s MCU programming, where he would receive the programming and assistance he required and still be at home with her in the

evenings. Allene felt “most comfortable” in this ALF which resembled their home in décor, and even thought Luke might eventually reside there. But for now she “was not ready to send him away.”

Allene had home health aide assistance in the evenings. After an unsatisfactory experience with a female aide, Allene found a male aide who was strong enough to handle Luke. He worked evenings, which allowed Allene to sleep. Allene continued to provide some of Luke’s personal care, which sometimes administering enemas for Luke’s constipation. She felt a sense of pride for providing Luke careful attention for such a personal need.

The MCU day program worked well for about a year, but as the MCU filled up and Luke stood to lose his place as a day-only participant, Allene felt compelled to accept the last remaining resident bed. Although Luke initially had to share a companion suite, an idea that repulsed Allene, a single occupancy suite became available a short time later. Luke has lived there for just over one year and Allene tries to see him daily.

### ***Theo and Mary Margaret Vance***

Theo is a retired white male, 72 years of age, who cares for his white 69 year old wife Mary Margaret, who is a former educator. In the summer of 2011 Theo will mark their 50<sup>th</sup> wedding anniversary after having known Mary Margaret since her freshman year in college. Both Theo and Mary Margaret have bachelor degrees. They have one child who died as a teenager and little other family. Still, Theo is close to his cousin and Mary Margaret’s sister who helped support Mary Margaret before her move.

Though Theo describes himself and Mary Margaret as being “very different,” he reminisces about their close friendship and close marriage that thrived on the pursuit of sports

like boating, golf, and tennis and travel to more 30 countries. Theo's work required him to live abroad and in several states enabling them to develop friendships across the U. S.

Theo first remembers noticing Mary Margaret's changes as subtle but significant about 1994 to 1995, though Mary Margaret's sister believes the changes actually began even earlier. Normally a "gregarious" woman, Mary Margaret became withdrawn and began forgetting words and skills. By 1996, Theo was becoming concerned for her safety, noticing that she might turn on the heat in the summer or the air conditioning in the winter or forget to turn off the stove. Theo took over meal preparation. On outings in their boat, Theo worried about Mary Margaret's safety while he steered the boat. He made up excuses about her car needing repairs until he finally sold it, knowing that she should not drive. When he could no longer leave her alone, Theo began to assume "full-time" responsibility for Mary Margaret, free-lancing at home as a consultant. Theo soon bought a motor home to provide Mary Margaret with a smaller living environment, and they traveled across the U. S. for three years. Eventually, Theo's "caretaking" became even more involved. Mary Margaret began requiring help picking out clothing and dressing. Theo brushed her hair and teeth. He watched her attempt in vain to apply her false eyelashes and tried to help her, but eventually simply put them away. Theo realized that the more help Mary Margaret needed the more he gave and the more dependent she became. The dependency created "a different kind of closeness," causing his feelings for her to change from love to "a lot of pity and a lot of guilt." Most regrettably, Theo realized in the fall of 2002 that Mary Margaret no longer knew him as her husband. At this point, Mary Margaret's sister, a mental health professional, suggested that it was time for them to move to Georgia so that she could help with weekly respite care. His cousin in Georgia offered weekly respite care as well.

When Mary Margaret became physically combative, Theo added home health aides. Eventually, Mary Margaret's combativeness made it difficult to maintain paid help at home.

Theo put considerable time into researching AD, contacting the Alzheimer's Association, searching the internet, and reading books and pamphlets, and listening to the advice of Mary Margaret's sister and the aides. He also had prior family experience with AD so he had some idea of Mary Margaret's anticipated outcome. In the summer of 2005, Theo concluded that he had run out of personal and financial resources to take care of Mary Margaret himself and began to look at NHs. In February of 2006, Theo sought a medical evaluation and professional medical advice for himself, with the result that Mary Margaret "had to go to a nursing home."

Theo only considered NHs because Mary Margaret's care "had to be covered financially." He specifically wanted a NH with a large MCU because Mary Margaret was very physically active and had a history of wandering. Though it was 45 miles from his home, Smithville Retirement Home and Nursing Care which met his criteria and there was an opening. In March of 2006, Mary Margaret moved into the Heritage Hall MCU where she continues to live. Theo's caretaking today involves driving to see Mary Margaret twice daily, morning and evening, so that he may feed her.

### ***Sandra and Jack Bradley***

Sandra is a white 59-year-old homemaker caring for her 61-year-old white husband Jack. They have one married son and one grandchild who live nearby, as well as Sandra's sister. They have known each other all their lives, having grown in the same rural area in Georgia, began dating when Sandra was 15, and soon will have been married 41 years. Sandra has a high school education and Jack has a college degree. Sandra is "numb" and still in shock over the seemingly sudden onset of Jack's illness and his rapid decline. It is very difficult for her to comprehend the

news from Jack's physician that Jack's demise may be within three years or less. Jack and Sandra are each other's world.

In 2009 Jack suddenly lost his high profile position with an international company. Looking back Sandra believes that the dementia was to blame, but the job loss shocked and confused her at the time. Atypical for Jack, who was highly respected and responsible on the job and at home, was his recent problem of losing keys and cell phones, missing flights and misplacing luggage. Sandra began noticing forgetfulness at home and Jack's difficulty with common tasks such as bill paying and making purchases. Their son Toby, who is close to both his parents, also noticed differences.

Sandra struggled to stay on top of Jack's new problems and protect him. She began to "hover over him" becoming a "mother hen" as she took over tasks. But, by the fall of 2009 she still was unaware of how ill Jack really was until Jack asked who Toby's mother was. Sandra quickly called her physician who advised her to bring Jack in for a series of diagnostic imaging tests that revealed Jack had had four strokes at undetermined points in time. Jack first received a diagnosis of frontal and temporal injuries and later of AD, after being referred to a specialist who hospitalized him for nine days for additional tests. Jack's symptoms were rapidly changing and his decline was sharp. Sandra continued to care for Jack and new symptoms continued to occur. Jack lost his ability to use his iPod, remote control, and guitar amplifier. There were hallucinations and agitation.

Jack's care soon became a "full-time job." Beginning at 4:30 a. m. Jack would rise and Sandra would give him toast and coffee and together they would watch the news. Afterward, she would make his breakfast, but they would "battle" for nearly two hours to get Jack to eat. Sandra next would bathe Jack, brush his teeth, and shave him before making him a healthy snack.

Afterward, Jack would watch more television, though eventually he lost interest in this activity. Sandra would serve Jack lunch at about 1:00 p. m. and afterward Jack might watch some television and snooze. When he woke, Jack would be given another snack before he rested again. Sandra tried to get Jack to go outside, but he no longer enjoyed this activity. Dinner would follow at about 6:00 p. m. and then Jack seemed to enter a restless period in which routinely he “would not even sit down” but would constantly pace throughout the house, upstairs and downstairs until nearly 2:00 a. m. Sandra, afraid to leave Jack alone, would walk behind him. One night Jack’s pacing stretched into 56 hours. Though Jack never wandered outside of their home, Sandra refused to leave him alone. She would call on their son Toby or her sister Billie to come over and sit with Jack so that she could shower. Sometimes Toby or Billie would also help feed Jack for Sandra. But, he would cry for Sandra when she was not by his side, wanting only her. Jack’s crying made Sandra feel as though she could not leave him, even to go visit her mother in a NH.

Jack’s behavior began to be even more concerning when he refused to take his medicine. A small delicately-framed woman, Sandra was easily overpowered by Jack, a tall, broad-shouldered muscular man. Jack began to lash out at Sandra, grabbing her and squeezing. One day he squeezed her hand until it broke. Jack had never shown aggression toward Sandra, and she was shocked and frightened for what might happen to him if anyone found out. Because Sandra was afraid that Jack would be taken away from her, she told no one and sought no help. Her petite hand healed into a misshapen form. Toby, in the meantime, became uncomfortable about his Dad’s hunting guns and knives and removed them from the home, though he knew nothing yet of his mother’s broken hand.

Jack required assistance with toileting, often urinating on the carpet and bathroom floor. Sandra bought incontinence briefs, but he would pull them apart. Sandra felt that she was reaching a breaking point. Her health was suffering and she “stayed sick all the time.” She didn’t have time to eat and rest. Finally, Sandra called a social service agency for assistance.

Sandra eventually confided in Jack’s memory clinic physician about his aggression. The physician admonished her to either to phone the police or her son when Jack next became aggressive, telling Sandra that “you don’t want your son to come over one day and find you dead.” Early in 2011, Jack fell and Sandra was unable to help him up. She called Toby, who directed her to phone for an ambulance. At the hospital, Toby saw his mother’s bruises for the first time, crying over the injuries. The hospital physician, who also saw the bruises, told Sandra that it was time for Jack to be in a NH. Nonetheless, Sandra took Jack home, but the very next week when Jack fell again, Sandra began “soul-searching,” ultimately realizing that both Jack and she needed help and decided to place Jack in a NH.

Billie began investigating NHs and Sandra received assistance from the hospital’s social workers. Sandra was concerned about Jack’s lack of health insurance, revoked when Jack lost his job, and finding a secure location. Billie soon found that a NH with an MCU and a good reputation near both Sandra’s and Toby’s homes. Sandra learned they could use a Qualified Income Trust to pay for Jack’s care and made the decision for Jack’s transfer to Heritage Hall at Smithville Retirement Home and Nursing Care where Jack remains today. Though Jack has just moved into the MCU, Sandra knows she will be pleased with the care and attention both she and Jack will receive because the NH has made a positive first impression on her. Just after moving into Heritage Hall Jack received a different diagnosis, one that fits his symptoms better along

with his rapid decline – LBD. Sandra does not know what that is and no one has given her much information about what to expect.

Sandra continues to spend each of her days with Jack from early morning to evening. Daily, she feeds Jack his meals and keeps him company. She cannot imagine her life without him and feels as if they both have “been robbed” and that she’s “thrown him away.” She still cries each day when she leaves Jack at the NH.

### *Profiles of Non-Spousal Informal Caregivers and Their Care Recipients*

#### *Marsha Balfour and Catherine Dunn*

Marsha is a married, white, 66-years-old, has a master’s degree, and has provided care in multiple settings to her 89-year-old mother Catherine for ten years. She has no children.

Catherine is twice widowed and holds the same Master’s degree as Marsha. Marsha’s brother and only other sibling, Harold, provides some emotional support to Marsha, infrequently visits their mother, and is involved in no decision-making regarding their mother’s care. Though his limited support has long been a source of stress to Marsha, she lately has begun accepting that they each have different priorities in their personal lives. Overall, Marsha is striving for a more positive and peaceful lifestyle now that her mother is living in the Cottage memory care unit at Meadow Manor.

Marsha has come to think of her mother as her best friend, though their relationship since Marsha’s childhood has been strained periodically. Marsha was young when her father died, and her mother made the decision to attain her bachelor’s and master’s degrees and she still keenly feels the loss of her mother’s redirected attention. Loss, in fact, overshadows how Marsha is making sense of her mother’s present cognitive decline, Marsha’s most difficult loss yet.

In the last ten years Marsha has helped Catherine make three moves to three different care settings, each providing successively higher levels of care. After the death of her second husband, Catherine moved into an independent living (IL) apartment where she lived for 5 years. While in IL Catherine began to experience intermittent problems with confusion and memory loss. She had difficulty handling her financial affairs and negotiating IL transportation for shopping and appointments. Eventually, Catherine struggled to navigate her way to the first floor dining room and began to miss meals and experienced confusion about the timing and location of activities. During this time Marsha began providing Catherine transportation and assistance with appointments and shopping and took over financial affairs. Marsha enrolled Catherine in an adult day program (ADP) three days a week that they both loved. Over her Catherine's protests, however, Marsha hired a professional aide to assist her mother during days and later added an aide to assist Catherine in the evenings. But none of these strategies fully solved the issue of Catherine's growing needs. Frustrated with care and care provider problems Marsha chose to provide all care for her mother for one entire month and found that to be an unsustainable solution as well.

Marsha next sought advice from a trusted friend who recommended a care agency professional to assist with additional care decisions. The care agency professional suggested that Catherine move to Meadow Manor, referring to it as the "Cadillac" of AL care. Marsha chose the largest two-bedroom AL unit available and spent considerable time decorating her mother's new apartment in the fashion of her mother's two previous homes. Marsha was shocked, when on moving day Catherine asked Marsha who Marsha's father was. Within two months Catherine was requiring ADL assistance and supervision beyond the scope of the AL care protocol and Meadow Manor's administrators suggested that Catherine begin spending days in the memory

care program as a transition to permanently moving into the MCU. Although Marsha insisted her mother would require a private MCU suite with a bathroom, none was available and three months later Marsha was given an ultimatum that Catherine must move into the MCU (in an available companion suite) or be discharged. Reluctantly and with a high degree of anguish, Marsha allowed the move seven months ago. Marsha now visits her mother once a week.

### ***Cecilia Beech and Janet Chester***

Cecilia, married, 51 years old, white, with a professional degree cares for her 85-year-old widowed mother Janet, a homemaker with a high school education. Cecilia and her husband have one son who is in college out of state. Cecilia works in a support position for her husband in his architectural firm.

Until just over three years ago Janet still lived in Cecilia's family home in a neighboring state. In the years preceding Janet's move from her home, Cecilia would drive several hours only intermittently to visit with her mother or assist her with small tasks. Cecilia's younger brother and only sibling Mitch had long lived closer to Janet than Cecilia and provided routine assistance as needed. In more recent years, Mitch had moved to the Midwest and no longer provided Janet with the same attention and care that he had in the past. Cecilia, who felt that she did not know her mother very well any more, uncomfortably assumed direct responsibility for assisting Janet.

Though Cecilia greatly loved and admired her mother and felt a strong obligation to see that Janet received the care she needed, she remained disturbed by a number of feelings. Cecilia resented her brother's reduced involvement in Janet's care, though she knew her feelings were unreasonable. She also resented her mother for the distance in their relationship. Janet and Cecilia's husband had a difficult relationship and some long-term tension also existed between

Cecilia and her husband. Worse, their only child was about to leave home and begin college at some distance away, a very difficult transition for Cecilia. Driving several hours one way to visit with her mother only added to the stress that Cecilia felt.

Changes in Janet that occurred before 2006 were subtle. She could no longer balance her bank statement and seemed. Cecilia believed that her mother was forgetting when she had eaten, and was compensating by eating more often, leading Janet to run out of groceries. Janet also was not monitoring her blood sugar or remembering to take medications appropriately. When Cecilia talked to Janet about needing help, Janet was resolved not to move from her home. Cecilia added a weekday home health aide to assist Janet, and over about 18 months, the aide's hours were increased as Janet's difficulties increased. On weekends the aide would telephone Janet several times to check in on her out of concern. Janet began to need reminders about wearing clean clothing, bathing, and tooth brushing. She left the stove on. When Janet began having problems with her gallbladder she had difficulty following her doctor's care instructions. Though she was receiving transportation assistance to get to physician appointments, no one was going into the exam room with Janet. Janet could no longer "make her own decisions and she wasn't making smart decisions." Without discussing it with her mother, Cecilia began investigating care communities where Janet lived and started thinking about how to get her mother to consider moving. She placed a deposit on an IL apartment at one nearby location. Then in one day of February 2007, Cecilia received two phone calls from Janet's aide and her neighbor. Both were concerned about Janet's ability to remain at home.

Cecilia contacted Janet's physician and learned that he had believed for the last six months that Janet had AD. Cecilia drove to her mother's home and quickly learned more about other poor decisions Janet had been making concerning her finances and health. Then quite

unexpectedly Janet had a serious fall resulting in a brain bruise that required hospitalization and recuperation in a NH. In a medical consultation Cecilia learned that her mother had been experiencing TIAs. Cecilia felt as if Janet “just came to the edge of a plateau and fell off and never went back up to where she was before.” As a condition of Janet’s release, hospital discharge planning required Cecilia to arrange 24 hour care for her mother. Cecilia had never considered that she needed supervision to that extent and was very disappointed that her mother required AL care rather than an IL apartment. From the fall of 2008 until the spring of 2009, Janet lived in an ALF near her home, made good friends with an AL neighbor, and was happy. During this time Cecilia learned Janet had developed VaD in addition to her AD.

Janet’s decline continued. She began falling in addition to requiring bathing and tooth brushing reminders. Eventually, Cecilia increased Janet’s AL care to the highest level. When Janet had a stroke in early summer 2009, the ALF advised Cecilia that Janet should be placed on the waiting list for the MCU. Cecilia felt overwhelmed that she “had to keep making these adjustments.” She “couldn’t see it,” though she eventually agreed, and when she thought about Janet’s move to memory care she “felt the enormity of shrinking her world.” When an opening in the MCU was delayed, Cecilia’s husband suggested considering MCUs near their home in Metro Atlanta. Cecilia’s brother advised Cecilia to make a decision that would make caregiving easy, pleasing Cecilia. Cecilia looked at nine facilities in a wide Metro Atlanta search and chose the location closest in driving time to her own home. Although at first she was turned off by Meadow Manor’s grandeur, her husband encouraged her to place Janet there nonetheless. He believed that the affluent location would attract the best staff, and that being recently opened, Meadow Manor would offer the best physical plant.

Cecilia knew little about dementia, but when she began reading about it she found the extent of the possible problems facing her mother to be shocking and began to feel the importance of making a decision for her mother's care. Finally, she decided for her mother to move into Meadow Manor in July 2009, accepting the last open bed in The Cottage MCU. The move was a confusing time for Janet who within the first week asked Cecilia if she (Janet) had ever had a husband. When Cecilia thinks of her mother's move to memory care she thinks of loss and how the move deepened both her own losses and those of her mother, explaining "You know we hear about things we lost in the fire? She [Janet] lost them in the move." Today, Cecilia visits her mother about once a week and is working on reconciling her losses.

### ***Dee Waterhouse and Fred Grant***

Dee is 57 years old, married, and white and cares for her 90-year-old divorced white father Fred. She has two sons, one of whom one is married with four children. Dee adores her grandchildren. She also has one sister, Sue, who resides out of state with whom she has a cooperative relationship for the care of their father. Like her father, Dee has a bachelor degree.

Dee feels closer to her mother Billie, Fred's ex-wife, than to her father due in part to Fred's history of mismanagement of the family's finances when Dee was young, which still "infuriates" Dee that and drives her resentment toward her father even today. Billie divorced Fred in the 1970s to salvage some bit of financial stability for herself. However, Fred and Billie have become roommates over the last 10 to 12 years because it was financially advantageous to share living expenses. Because Dee's father continued to make unwise financial choices in his later years, Dee and her sister "kinda took control and did the legal things we had to do, paid the bills and things." She explains that their father "was about to do himself in again" financially.

Though Dee distances herself from Fred emotionally, she recognizes several positive qualities, such as his helpfulness and his ability to get along with others. Relief is a chief outcome for Dee regarding Fred's placement in an MCU as she had difficulty investing herself in the caregiving that Fred's decline required.

Sometime between 2006 and 2007, the family began to notice something different about Fred. He began to have trouble remembering things like appointment dates. He was enrolled in an ADP by 2008 and sometimes experienced confusion about his schedule. The family did not think Fred had health issues though they later found that he was irreparably blind due to a brain injury probably caused by a fall that no one knew had occurred.

According to Dee, Fred's living arrangement with Billie was strictly for financial convenience. However, Billie provided significant routine assistance to Fred as his needs increased. Though Dee took Fred to his physician appointments, Billie made sure Fred had his medicine every morning and evening, took him grocery shopping, and provided his transportation to his ADP twice a week. She even drove him the 8 miles to and from Dee's home when Fred had supper with Dee and her husband.

Dee and her sister Sue began to become more concerned about their mother when Fred began requiring even more assistance from Billie. Billie complained to her daughters about Fred and was growing tired of assisting him and they felt a need to protect her. Fred still enjoyed using the stove to heat soup and sometimes forgot to turn it off. Fred began sleeping more during the day, which disturbed Billie's sleep. Dee and her Sue began to be concerned about Billie's quality of life. They chose not to use home health aides, but instead decided it might be time to for their father to move out of their parents' apartment, although the move would also affect Billie's ability to remain in her apartment and her independence. Soon afterward Dee and

her sister also began having conversations with Fred's physicians, who believed that Fred did not have AD but instead was experiencing "normal getting-older-dementia." At no time was it ever an option for Fred to live with Dee. For Dee, "it's got to be a place like this."

Both Dee and Sue looked at ALFs near their own homes for about six months, believing this is what their father required. Dee looked at local area facilities that she had previously considered with her husband for his mother. Sue looked into a facility near her out-of-state home deciding that she did not care for it. But, Sue did notice that the facility had a newly-opened sister facility near Dee's home and asked Dee to investigate Meadow Manor. When Dee met with administrators there she learned that Fred's needs better fit criteria for residency in The Cottage MCU instead of in AL. Once explained to her, Dee easily agreed that "the back part was definitely the right part for him."

Fred moved into The Cottage at Meadow Manor in the fall of 2009 where he remains today. Dee visits him a couple of times a month because she has "to be in a certain frame of mind to see" him. She prefers to visit in the afternoons when most other MCU residents are resting since she finds the activity and atmosphere of The Cottage "depressing." She believes that she and her sister "definitely made the right choice." She views this time in Fred's life as coming "full circle" and that "all of the sudden you're doing everything for your parent like you did for your children" though she recognizes that unlike herself, "there are people who can't afford places like this and are actually bathing them and changing them and everything." Billie moved into Sue's home out-of-state.

### ***Jilly Thornton and Anne Littleton***

Thirty-seven-year-old Jilly is a white business owner with some college. She is the youngest of her 70-year- mother Anne's four daughters who range in age from 37 to 47. Jilly is

married with a young daughter. Anne, divorced twenty years, has no contact with her ex-husband. Three of Anne's daughters live near Anne's NH. One lives out of state. Anne's two youngest daughters, Jilly and Jessie, have the most in contact with Anne. Anne has had a troubled relationship with her eldest daughter, who lives locally, and they only see each other occasionally, although this daughter adopted Anne's little dog when Anne first moved into a NH. Anne rarely sees her second eldest daughter who lives out of state, and according to the youngest sister, is not convinced of her mother's illness. Jilly not only spends the most time with her mother, visiting her weekly, but is the NH's contact for Anne.

Jilly sometimes has trouble knowing whether her mother's behavior is caused by her illness or simply consistent with her life-long erratic behavior, often thought of by her four daughters as "selfish" and manipulative. Jilly and her three sisters shared a less than stable life with their mother, even before Anne's divorce from their father when Jilly was a young teen. The sisters have come to distrust their mother and each other. Still, Jilly loves her mother and wants Anne to have the help she needs.

Anne has always been a bit of a free spirit, changing jobs and moving around. Jilly admires her mother for obtaining her nursing license after her parents divorced. When she was younger, she had fun traveling around with her mother, who seemed to always be going off on "adventures." Jilly also admires her next older sister Jessie, who helps look out for Anne. Though just two years apart, Jilly and Jessie have led distinctly different lives. Jessie has a college degree, a "prestigious" job, and the "picture book life. It seems that all four sisters always had different perspectives on their mother. Their mother's historic inconsistencies add to the confusion. When Anne was in her late 50s and early 60s she had trouble keeping nursing jobs and struggled to reach age 62 before retiring.

Jilly knew that Anne had “always been going to the doctor a lot of the time” and that Anne had “always been on a lot of different medications.” Then at about age 64 or 65, Anne “took it upon herself to get the [AD] diagnosis with the dementia,” which Anne promptly discussed with all four daughters. The daughters believed the revelation was just “a plea for attention again” and they “couldn’t see anything wrong with her.” Anne’s subsequent diagnosis of PD complicated her medication routine, adding to the confusing array of information and symptoms that Anne’s daughters were processing.

After a time Anne left Georgia on another of her “adventures”, this time to a western state to live with her sister. But as time passed Jessie became concerned enough about Anne’s medical care that she flew out to her mother’s location and drove her and her possessions back to Metro Atlanta. Over the next two years the daughters began to take notice of how Anne’s “mental stability was deteriorating,” and that Anne was no longer following her medication protocol. Anne began having difficulty remaining independent.

Anne’s driving skills deteriorated and her daughters asked her to stop driving. Though initially angry with the confrontation, Anne understood, sold her car, and Jilly began taking her mother to physician appointments. Anne’s neighbors in the senior high rise were also taking note of Anne’s difficulties living alone and suggested that Anne should move to a NH. Anne fell and hurt her back. She trapped herself in the building’s stairwell. She seemed to constantly walk her dog, as if she had forgotten previous walks. Anne’s inability to properly take her medications also led to physical problems, leading to “dilated” eyes and “sweaty” skin. Worse, Anne would go “just completely out of her mind” sometimes. At first, all three of Anne’s local daughters took turns assisting with her three-times-a-day medication routine, realizing that this

was “a very temporary solution.” Jessie also began investigating NHs for Anne, the only solution since Anne had no income other than Social Security.

In late 2009, Anne moved into the general population of her first NH, located by Jessie and Jilly. To combat her anxiety over the move, Anne was given a new medication. Unfortunately, the medication resulted in the onset of hallucinations, combativeness and aggression, hot flashes, sweating, urinating in inappropriate places, and Anne’s subsequent hospitalization in a psychiatric facility. During Anne’s hospitalization, Jilly and Jessie located a small ALF for Anne, which they believed would be an appropriate and much better environment for their mother than the anxiety-inducing atmosphere of the first NH. However, within two days of moving to the ALF, Anne experienced another psychotic episode and eloped, requiring emergency personnel to assist in her return, followed by a second psychiatric hospitalization. The hospital then assisted with locating a second NH for Anne close to her two youngest daughters and discharged Anne into the NH’s MCU, described by Jilly as “a very small lock-down unit ... full of crazy people.” Anne was very unhappy and asked her daughters to move her. Anne then was transferred to Heritage Hall, Smithville Retirement Home and Nursing Care’s much larger MCU.

Jilly remains ambivalent about the cause of Anne’s problems not knowing what or how much is related to medications, diagnoses, or Anne’s history of unpredictable behavior. Jilly knows a little about PD. Her mother provided her a book that helped her better understand PD. Anne also provided Jilly some information about dementia, but Jilly didn’t read much about it. All she knows is that “there’s a place in your brain that’s just rotting away. It’s just leaking away somehow.” Jilly has also seen information on the television and has heard about President Reagan’s experience with AD. She thinks of dementia as diseases that can make an individual

become “a really mean person and say things that they wouldn’t normally say [and] forget you.” Jilly feels some amount of guilt about not having her mother live with her, but she stands firm; that will never happen. Jilly knows that she and her mother would have relationship problems and that having Anne live with her would curtail Jilly’s ability to enjoy her relationships with her husband, her daughter, and her friends.

***Pamela Hamm and Theresa Keller***

Pamela, a married 66-year-old white healthcare professional, is the caregiver for her sister, Theresa, a never-married 68-year-old white retired federal employee. They are the only two surviving siblings of four children. Pamela and her husband have four children and seven grandchildren. Theresa never married nor did she ever have any children. Both sisters have had long professional careers and both have college degrees. When Theresa retired in about 2002, she moved to the Metro Atlanta area to be near her sister and took an apartment alone. The two sisters had never been close or known each other very well. Pamela made a point of telling Theresa that she wanted to be part of Theresa’s life, but not the focus, as she believed Theresa would expect.

Theresa attempted a part-time job, had a minor accident, and never became involved in outside activities or made friends. Theresa’s reclusiveness annoyed Pamela. When their brother decided to move to the area, he moved in with Theresa, but the two of them did little but share apartment space. According to Pamela, Theresa’s pursuits were smoking cigarettes, drinking Pepsi, and watching television. Theresa gradually began to change by the beginning of 2009. Her monthly expenditures were more than her small income. She ran out of her savings and exhausted the funds that Pamela and her husband had given her. After living in her apartment for more than three years, Theresa had not hung a single picture and the amount of clutter

seemed to point to a habit of hoarding. Over time, her clothes were becoming damaged and burned with holes. Pamela estimated that Theresa's cigarettes cost about \$400 a month, saying, "It was unbelievable how much money she [Theresa] smoked away." Worse, Pamela "was terrified she was going to start a fire!" Theresa was a diabetic and the constant Pepsi drinking caused frequent spikes in her blood sugar. Theresa also experienced episodes of confusion. One trip to Kroger turned into five lost hours in the store and at other times she lost her way driving in familiar areas. She began to neglect her hygiene. She became dependent on Pamela for transportation to the grocery store and her physician. Pamela believed that all of Theresa's "life choices" were leading Theresa "to being a sick woman whose mental status declined." Pamela felt that she only had so much of herself to offer Theresa, whose needs were growing. She had done considerable other family caregiving over the past years and was unwilling to take on more. She now had her own life to live and knew without a doubt that she could never allow Theresa to live with her.

Pamela knew about dementia because of her education and her work. She didn't feel that giving dementia a particular name mattered. "You can call it dementia. You can call it Alzheimer's, anything you want. But, the bottom line is you're dealing with someone who doesn't know how to turn around," she explained. As a healthcare professional, she also knew what was required for NH placement, the only type of care facility that Theresa would be able to afford. When the opportunity presented itself, Pamela decided she would help Theresa move into a NH.

Unexpectedly, in the fall of 2010, Pamela's opportunity came. Theresa was not feeling well and Pamela took her for a check-up. Theresa's physician immediately found that she had serious physical health issues that required hospitalization. Pamela knew staff at this location

and made a point of having conversations with them about Theresa's need for a NH. She knew that Theresa "would have a perfect [NH] entry for Medicare." Pamela already knew of Smithville Retirement Home and Nursing Care and suggested it for discharge planning. Pamela also retained a lawyer to have essential power-of-attorney documents drawn up for Theresa to sign. She investigated and sought a Qualified Income Trust for Theresa to assist with Theresa's expenses. "The attorney did her will, her power-of-attorney, her durable, her medical power-of-attorney." Theresa signed everything. Pamela wasn't really sure how well Theresa understood the process, but Theresa was able to give answers "to the questions that were put to her."

At the end of her hospital stay, Theresa was transferred to the general population of Smithville Retirement Home and Nursing. But, Theresa kept attempting to leave and in the end, approximately two months after she had moved into the NH, the NH decided that Theresa must be admitted to their MCU, Heritage Hall. Pamela is disappointed that Theresa must live in Heritage Hall and hopes that Theresa may be allowed to try living in the general population again in the near future. Pamela also hopes that AL regulations regarding Medicare will change to allow Theresa to move out of the NH altogether at some point. But for now, Pamela will be her "sister's best friend. [She'll] be whatever [Theresa] needs [her] to be a couple of times a week.

## CHAPTER 5

### CAREGIVING FOR PERSONS WITH A DEMENTIA

This chapter is comprised of two main sections: 1) a description of the study participants' progression into primary informal caregiver roles for persons with a dementia, including becoming aware of the care recipients' cognitive changes and transitioning to caregiving roles, and 2) the study participants' experiences of being caregivers, including a discussion of caregiving duties, informal caregiving networks and use of formal care services. These early elements provide a foundation for recognizing the multilevel factors that compel caregivers to make decisions for care recipients' moves to memory care and to better understand the decision-making processes.

#### *Becoming a Caregiver*

*“It was something that I had to get accustomed to.”*

Becoming a caregiver can be life-altering, producing paradigm shifts in lifestyle and relationships, sometimes in conflict with new responsibilities. Caregivers must focus not only on necessary tasks in the here and now, but may face decisions for the future welfare of another individual all while recognizing, meeting, or ignoring their own needs. The following two sections explore how the study caregivers recognized and made sense of the changes they encountered and transitioned into their new roles, exposing them to new stresses with its subsequent and necessary problem-solving. Table 5.1 presents care recipients' varying living arrangements at the apparent onset of dementia. Five lived in their own homes with their spouses while two lived in their own homes with other relatives. Three others resided alone, one in her own home, another in a senior apartment, and a third in IL.

**Table 5.1 Care Recipients' Living Arrangements at Apparent Onset of Dementia**

<b>Living in Own Home with Spouse</b>	<b>Living in Own Home with Other Relative</b>	<b>Living Alone In Own Home</b>	<b>Living Alone in Senior Apt.</b>	<b>Living Alone in IL</b>
Roger Chatham John Harrow Luke Ballentine Mary Margaret Vance Jack Bradley	Fred Grant (living with ex-wife) Theresa Keller (living with brother)	Janet Chester	Anne Littleton	Catherine Dunn

***Becoming Aware of the Future Care Recipient's Cognitive Change: "It was out of character for my mom that she was doing weird things."***

According to Reba Chatham, who cared for her husband, Roger: "You don't know when this has been going on until you look back and you see and aaahhh, now that's computing." Like Reba, all other study participants regarded care recipients' earliest changes as so subtle that they were nearly imperceptible. None recognized that a dementia was the cause. "I really didn't notice anything initially," said daughter Marsha Balfour. Sandra Bradley agrees about her experience with her husband Jack: "I just wasn't putting anything together that something was wrong with him, you know." "Of course I didn't know what was happening at first, you don't know," says husband Theo Vance.

Caregivers rationalized future recipients' changes and new behaviors with what they already knew rather than associating the changes with the new phenomenon of a developing dementia. Some caregivers, all daughters, reasoned that their future care recipients' changes were due to long-familiar negative behaviors. Marsha Balfour and Jilly Thornton linked their mothers' incidents of change to personality traits of control and selfishness. "My mom is very manipulative, so you never quite knew what was going on there," explained Marsha. Jilly believed her mother "just wants attention," explaining, "She's always been kind of a selfish

person.” Dee Waterhouse had long ago intervened in her father Fred Grant’s financial affairs due to “his stupidity,” regarding finances. Dee was used to handling Fred’s business affairs and stated about his behavior, “You can’t relate that to his mental state and old age.”

For some caregivers, changes appeared to be related to old dependencies or the emergence of new needs. Cecelia Beech deemed that her mother’s lifelong lack of self-confidence explained her new problems: “I just had to talk to her a lot . . . it was my job to convince her that she could do it.” Theo Vance found that his wife “became withdrawn” because in his view, “She lost confidence in herself.” Similarly, Allene Ballentine noticed that her husband “relied” on her more than previously. She explained, “He would follow my lead where he would [in the past] take more of the initiative. I didn’t pay a lot of attention to that.”

Other caregivers searched for meaning in new and odd behaviors or disposition. Annette Harrow felt that her husband John’s moods had changed, recalling how early on when he was “behaving a bit strange” she was prompted to ask a brother-in-law, “Can you watch him for me?” Some caregivers associated behavioral change with the occurrence of a significant life event, such as an abrupt job loss or recent retirement. Sandra Bailey’s husband Jack’s problems seemed to surface near the time of his job loss.

This was happening then and I didn’t know it and the company was having problems and he was let go. And, as I think back I really think it was he had been with the company quite a while . . . I think his condition was beginning to develop then and rather than tell me that he was not really doing his job up to par they told me that they were just, he was one of the ones. They were dividing up the company and were just going to let him go. And, I couldn’t understand that because he had been with them so long and why would they let him go?

Of her sister Theresa Keller's retirement Pamela Hamm said, "I don't think she's done ANYthing since she's retired. She sat in front of the TV and smoked all day. That's it."

Likewise, when Reba Chatham's husband Roger retired he gave up important hobbies and lifelong interests. Reba believed that Roger "was just really stressed from just pushing and pushing" explaining: "I think the man just began to wear out. I think he just got tired."

When confronting and attempting to understand the true nature and meaning of the changes care recipients were undergoing, caregivers experienced strong emotional reactions. Some caregivers were stunned. Wife, Reba Chatham says, "I'm not really sure what I felt. I think I kinda went into neutral." Allene Ballentine, a spouse, chided herself, "I said, you dumbass, you should have known what was going on .... I was in a state of shock." For Sandra Bradley, her husband Jack's changes were too perplexing to comprehend. She explained, "I just can't understand some of the things that go on in his mind. I don't know how to accept it."

### ***Transitioning to the Caregiving Role***

Because of the very different nature of the two types of relationships, spousal caregivers and non-spousal caregivers experienced their caregiving transitions differently. The couple-identity of spousal caregivers was an important factor in committing to new spousal roles. Non-spousal caregivers developed their new roles in the shadow of unresolved family relationships. Because of these differences, spousal and non-spousal caregivers will be discussed separately in the following two sections which provide some insight into how each group of caregivers incorporated their new roles into their lives as well as some of the feelings they experienced.

***Spousal Caregiving: "You've gotta show them how to do things until they just can't do them and then you've gotta do them for 'em."*** At the apparent onset of symptoms, all spousal caregivers resided in their own homes with the care recipients and no other household members.

Each couple was in a long-term marriage of at least four decades. All future caregivers were deeply invested in their partners and marriages and dedicated themselves to their new caregiving responsibilities with strong commitment to the task and profound respect for their care recipients' dignity. For Sandra Bradley, taking care of her husband following the onset of his dementia was similar to how she related to him before, only now with increased attention. She explained, "You can see how I hover over him .... I've always tried to do everything and anything ... I'm a mother hen anyway ... I just tried to get to it before he did because I just didn't want him to be upset." Two spousal caregivers, Theo Vance and Allene Ballentine, stopped their paid work endeavors to focus full-time on their spouses' needs.

For two caregiving wives, Reba Chatham and Annette Harrow, beliefs and values associated with marriage vow promises were essential to how they interpreted their new roles within the marriage relationship. Reba shared this: "People have said to me, 'I really admire your decision for taking care of your husband.' I've said, 'What do you mean? There is no decision. I'm married to this man.' You don't make a decision. You just do it. It comes with the territory." Annette agrees, "The time has come to think about your marriage vows and you have to accept whatever."

Another illustration shows the effect of Southern culture on caregiving beliefs and values. Both Sandra Bradley and Reba Chatham readily identified with the impact their southern, and in particular, South Georgia upbringings had upon the manner in which they related to their husbands as men and marriage partners. Both women remained concerned with preserving their husbands' dignity as men, carefully orchestrating how they approached assuming responsibilities formerly held by their husbands. Sandra explained: "I didn't want him to feel less of a person, certainly less of a man." Reba agreed: "There's a mindset [that] the woman is the one that ...

just takes care of that husband! There's that other mindset where the husband is in control of everything." These same principals also figured prominently into how Reba and Sandra faced the changing balance of their relationships with their husbands, an issue faced by most of the spousal caregivers.

Adapting to caregiving roles created changes of balance for marriage partners and their relationships. All spouses but Annette Harrow eventually expressed feeling somewhat parental toward their care recipients in regard to this evolving imbalance and associated some level of child-like qualities with their spouses. Theo Vance described the transition as going "from being a partner, having a companion, to being a guardian" and changing from "a spousal relationship to almost caring for a child." He said: "It's like caring for a child in that you've got to. You don't progress. But, it's very similar in that you've got to show them how to do things. Unfortunately, they don't pick it up and continue doing it." Allene Ballentine, however, was careful to counter with a slightly different perspective, saying that Luke was "somebody I had to take care of and it wasn't a child, it was an adult that had to be taken care of."

For Reba Chatham, two changes were evident, one negative and one positive. First, sexual intimacy began to feel inappropriate and she reached a point when she was no longer able to relate to Roger in this way. A more positive change involved a shifting power balance in Reba's 55-year marriage. She described this change: "I began to give input .... He gradually saw that I was capable, that I could do it .... He learned that he could trust me explicitly and, uh, that I would take care of things and that I had his best interests at heart."

***Non-Spousal Caregiving:*** ***"I know she's really sick and I completely get that and do what a can to help her out."*** Adaptation for non-spousal caregivers, four daughters and one sister, was somewhat different than for spouses. No caregivers in this group lived with the care

recipient at the point of the apparent onset of symptoms or at any later time. Moreover, three emphatically declared that their care recipients could not live with them. Three of these care recipients lived alone in their own homes. The two others shared their homes in a roommate-type situation, one a sibling and one with an ex-spouse. Neither had close relationships with their familial roommates. Four of the non-spousal caregivers were daughters. The fifth was cared a sister.

In each of these non-spousal cases, following the apparent onset of symptoms, negative aspects of prior family relationships began to surface. Daughters Marsha Balfour, Dee Waterhouse, and Jilly Thornton each recall disrupted family life in their girlhoods that fuels their present day anger and resentment and affects how they relate to their parents today.

Marsha recalls feelings of abandonment regarding how her newly-widowed mother, Catherine Dunn, turned her attention to continuing her education. Catherine's attention to Marsha is ebbing once again, this time because of dementia, generating Marsha's reluctant "process of letting go." Dee remembers her father Fred's careless financial decisions, resulting in the end of her parent's marriage, and the responsibility she and her sister later assumed as adults because of her father's "stupidity." Dee has "to be in a certain frame of mind to see" Fred because their family history still "infuriates" her. Jilly grew up with inconsistency and developed a sense of distrust of her mother. She derives security from the care boundaries she has set.

Though both Cecelia Beech and Pamela Hamm make efforts to acknowledge positive attributes of their care recipients, they acknowledge that they do not "understand" them, limiting the extent to which they are able to personally connect. Cecelia and her mother, Janet Chester, grew apart after Cecelia left home decades ago. They were never able to strengthen their bonds.

“We both had to rely on what we knew about each other from the past because we didn’t spend enough time together to know each other as in the present,” Cecilia explains. In addition, financial decisions that Janet made contrary to Cecilia’s advice anger Cecilia, causing resentment, worry, and difficulty if not considerable expense. Cecilia works to manage these feelings without her mother’s participation. Pamela has never been close to Theresa Keller, the sister for whom she is now responsible. Pamela maintains that she and Theresa don’t “have anything in common” referring to their “different interests.” Pamela resents Theresa’s “death wish” and other self-destructive behaviors. Pamela never wanted to become Theresa’s lifeline and recognizes how her feelings restrict her involvement in Theresa’s care.

### *Being A Caregiver*

*“It got down to the business of it was increasingly important to take over.”*

Just as there were differences in the way that spousal and non-spousal caregivers transitioned into their new roles, so were differences evident in how those roles were performed, including when and how caregivers sought the assistance of others, both informal and formal care providers. Spousal caregivers daily and directly participated in the physical care of their care recipients, supporting them with hands-on ADL attention prior to the moves. Non-spousal caregivers supervised the needs of their care recipients but were by and large less active, sporadic, if not uninvolved, in the day-to-day ADL needs of their recipients. All caregivers provided some form of routine IADL assistance with spousal caregivers integrating IADL responsibilities into their routine carework as necessary, in the beginning only making arrangements for assistance when unable to perform IADL duties.

*Spousal Carework: “You would not believe how time consuming it is to have someone at home.”*

During the time that their care recipients were in the home, spousal caregivers described their daily carework similarly: “taking care of everything”, “responsible for everything full-time”, “a full-time job”, “it’s a 24 hour-a-day job”, “couldn’t control him .... couldn’t take care of him.” With one exception, Annette Harrow, whose husband John performed all his own care, all spousal caregivers provided ADL care for their spouses until, in the case of three caregivers, formal in-home aides were hired to assist part time. Table 5.2 illustrates spousal care tasks.

Table 5.2 Spousal Care Tasks

		<b>Reba Chatham</b>	<b>Annette Harrow</b>	<b>Allene Ballentine</b>	<b>Theo Vance</b>	<b>Sandra Bradley</b>
<b>ADL Care</b>	<b>Bathing</b>	X	NN	X	X	X
	<b>Grooming Tasks</b>	X	NN		X	X
	<b>Tooth Brushing</b>	X	NN		X	X
	<b>Toileting</b>	X	NN			X
	<b>Incontinence Care</b>	X	NN	X		X
	<b>Enemas</b>		NN	X		
	<b>Feeding</b>	X	NN	X		X
	<b>Dressing</b>		NN		X	
	<b>Choosing Clothing</b>		NN		X	
<b>IADL Care</b>	<b>Bill Paying/ Finances</b>	X		Typically Conducted		X
	<b>Grocery Shopping</b>	X	X	X	X	X
	<b>Meal Preparation</b>	X	X	X	X	X
	<b>Medical Appointments</b>	X	X	X	X	X
	<b>Transportation</b>	X	Public Trans.	X	X	X
<b>Medication Management</b>	X	X			X	
<b>Managing Problem Behaviors</b>		X	X	X	X	
<b>Fall Prevention</b>	X			X	X	
<b>Wandering Supervision</b>	X	X		X	X	
<b>General Home Safety Issues</b>	X	X	X	X	X	

X=Care Task Performed

NN= Type of Care Noted as Not Needed by Care Recipient

Personal care provided by spousal caregivers generally included bathing, tooth brushing, shaving, hair brushing, toileting, incontinence care, and for one spousal caregiver, giving enemas. Choosing clothing and dressing for the day were also important daily caregiver responsibilities. Gender influences in ADL care were most apparent for husband Theo Vance who recalls how in addition to brushing his wife's Mary Margaret's hair and helping her brush her teeth, he found that his wife "couldn't figure out basics like ... what to wear." He "had to do those things, help her with those things, or remind her," but when it came to the false eyelashes

that Mary Margaret had always worn he could only offer suggestions until eventually he “just put them away and she just forgot about them.”

Bathing, toileting, and incontinence care seemed to be particularly difficult and labor-intensive tasks. “It got so that I would have to put him in the shower and end up that I would have to physically bathe him,” Sandra Bradley recalls. She found that, “He would stand, just stand in the shower .... I would go, ‘OK,’ and put some shampoo on his hand.... He just can’t remember.” Sandra “had to do the toileting as well” requiring her “to take him to the bathroom” where he “would urinate on the carpet.” When Sandra bought incontinence products to use with Jack, they were just as problematic because Jack would simply “pull them apart.” When Roger needed toileting Reba Chatham “had to be right there with paper towels and sit him down and all that.” Reba explains further: “He had gotten to the place where I had to put Depends on him ... he’d go to the bathroom, he’d puddle. He’d get up from the toilet and stream whatever he was doing across the floor.” For Allene Ballentine, there were times when she “was changing beds in the middle of the night” and there were times when Luke was lying “on the ground trying to get something to come out” after she had given him an “enema.”

Bathing and undressing in particular were activities that were emotionally tangled with intimacy transitions for one spousal caregiver. Reba Chatham’s husband Roger remained sexually attuned to her presence. She began delaying undressing to avoid stimulating him. Reba also reached a point where she was no longer able to “bathe him.” She explained

“[Roger] didn’t have the understanding that he just couldn’t grab and do what he wanted to do and as far as he wanted to do it. And, I just worked with him until I couldn’t work with him anymore. He got to be too much .... It felt like incest .... It’s been a challenge for me, to know where to draw the line and when you take care of

yourself and when you know this is not going to happen. It WON'T happen. It CAN'T happen.”

Assuming IADL care also included the challenge of taking on new responsibilities in the home for some spousal caregivers, tasks both they and their care recipients had once been engaged according to traditional gender roles. After Mary Margaret became ill, Theo Vance became responsible for meal preparation and Mary Margaret's medications. Theo noted

So, uh, she would just stay in the bedroom a lot while I would do things and stay in the family room, whatever. I had to fix dinner. She'd quit cooking and I'd ask her to help and she just didn't want to be involved in anything after it got so bad in '97.

For the wife caregivers, meal preparation was typical of their carework duties, as was control of medications. But, other home tasks weren't. Reba Chatham became newly proactive about home repairs and lawn maintenance, making decisions to hire professionals to complete work that previously was her husband's domain. She explained

The neighbors started helping. Then I told Roger, 'You got to show me how to use the lawn mower or I'm going to have to hire somebody.' And, he said, 'You ain't got any business mowing that grass.' Then I said, 'Well, we're going to have to hire somebody.' So, um I started having to do that.

Both Reba and Sandra Bradley took on bill paying and other financial decisions for the first time, though Allene Ballentine had always taken care of these duties in her more egalitarian household. Reba and Sandra shared their experiences. Reba noted: “He was paying the bills for a little while. And, then it got so difficult for him to do that and I started just gradually taking [care of] that.” Sandra's experience of assuming bill paying responsibilities was similar

I was making dinner one night and had no idea he was sick, of course, and he was paying the bills that particular month and he was sitting there and I noticed he was voiding a check. Well, he was voiding another check, a third check. And, I said, 'Jack, what's wrong?' He said, 'I just can't write this check.' He could not write the check! I mean he absolutely could not figure how to write the check out. And, I could not understand why he voided three checks and I had to finish the checks. After that I had to take over.

Four caregivers found themselves in the position of making decisions about their spouses' driving abilities and car use. Reba Chatham enlisted the assistance of her adult children to appeal to Roger on behalf of his safety before taking over transportation responsibilities in their household. Reba remembered

The doctor stopped him from driving .... [Roger] said, 'I'm not listening to that Doctor and I'm not going back either.' And, I said, 'Because you don't like what he said?' He said, 'Yeah!' .... And, I said, 'Let [daughter who is a nurse] come over and get the perspective a nurse and one who has done home healthcare and as a daughter.' .... So, she came over and she said, 'Dad' and we never use this kind of language, and she said, 'Dad, I know you're pissed off 'cause you can't drive.' So that got his attention. She said, 'I understand and I don't blame you, but let me tell you something.' She said, 'this is because we love you' and explained about her husband's parents and what happened with them, they got in a wreck and ended up in a hospital and .... you're not going to have to stop anything, mom's going to take you!'

Theo Vance found himself making excuses to his wife Mary Margaret about her car's needed repairs until she finally "forgot" about the car and Theo sold it. Theo explained

Driving, driving, that was one I didn't mention. For instance, when I quit my job I was afraid of her driving and I talked to enough people, and at the time I think I only knew wives whose husbands had gone into dementia and men, Evidently, are really difficult to get the keys away from. Mary Margaret wasn't such a problem, because I'd say, let's come on and go and I'll drive. And, when she'd bring up her car, I'd say the battery's not working, we've got to get that fixed. Come on, well go in my car. And, so eventually she just forgot about that and I just sold the car.

When Luke Ballentine totaled his car, Allene simply declared, "That's it dear!" After Sandra Bradley's concerned son learned that his father's physician's advice was that Jack should no longer drive, he confronted his mother, who then sold Jack's new car. Driving was not an issue Annette Harrow had to tackle. She and John already relied on public transportation or riding with others when traveling, but Annette took great care to accompany John on trips or outings so that he did not become lost. For all other spouses, with the exception of Sandra Bradley, providing transportation for outings and medical appointments was common. Because of a prior medical condition, Sandra did not drive and relied upon assistance from her son and sister for Jack's needs. One care recipient, Luke Ballentine, was also driven daily to his adult day program by his wife, Allene.

Care recipients' behavioral changes created demanding challenges in the home, if not serious safety issues. Supervising active and ambulatory care recipients required considerable

time for spousal caregivers. Combative or aggressive behaviors were especially difficult.

Caregivers developed a variety of strategies to combat these challenges.

Falls were a constant worry for some caregivers. Reba Chatham noted that she “was having to watch [husband Roger] more and more and make sure he didn’t fall, make sure he didn’t decide he wanted to go up the stairs by himself.” Sandra Bradley was just as compelled to watch her husband Jack closely. She explained: “Every move he made I was awake. I was afraid he would fall. I don’t why I was behind him. I couldn’t hold him up .... I thought I could break his fall is what I was trying to do. I was trying my best to help him from hurting himself if he fell.”

For four of five spousal caregivers, issues with wandering began to occur. Both Reba Chatham and Theo Vance changed and added additional door locks to help keep their spouses from eloping without their knowledge. Theo recalled

I put a double lock on the door and one of them was up on the door where she couldn’t reach it. So, eventually she really resisted that at first. And, I got a few words about that, but after awhile, she got over it and would stay in the house. Doesn’t mean that she didn’t look for ways to get out, but ... I’d figured out how to keep her in.

Sandra Bradley followed her husband everywhere inside the home. She “was not about to go to sleep and leave him up. He could go downstairs and out the door.” Annette Harrow’s experiences were the most eventful. She followed her husband closely and he still continued to elude her. When she and John moved into their daughter’s home, the sofa was placed in front of the door nightly before sleeping to impede John’s escape. Sometimes John awakened during the night and began packing to leave.

Annette explained

He was just refusing to come home. So, when she [the daughter] saw 9 [o'clock], 10 [o'clock], 11 [o'clock], going to 12 o'clock, right after that she was the police on his patrol .... So, when she saw it was near midnight, she stopped the police car and asked whether they would bring him home .... They brought him home and he sat on the porch and he refused to come indoors .... So, after about twenty minutes of just refusing to come in the police called for the ambulance. The ambulance came and he just refused to come into the house. So, they put him on the gurney and brought him inside.

Mary Margaret Vance exhibited a similar need to wander. Theo talked about his technique for addressing his wife's behavior

Mary Margaret used to pack up, pack up suitcases and everything she owned several times a day, put them by the door and wait for whomever was going to pick her up and we'd sit there and wait for the person and he or she wouldn't show up. So, we'd unpack and so I finally figured out we needed fewer things to pack. So, her things started getting hidden and donated. I got her down to one suitcase. She'd take her suitcase when somebody wouldn't come and start walking. I'd walk with her. And, I'd let her carry the suitcase so she'd tire out. And, so we'd go back home when she tired out.

Three of five spousal caregivers also experienced problems with combative or aggressive behaviors. According to Annette Harrow, John's "moods" sometimes resulted in his striking out physically. In one instance when a female emergency technician responded to her call, John "took the bag from her and pelted her," causing law enforcement to be called. Mary Margaret Vance began to lash out at aides in the home, making it difficult for her husband Theo

to retain in-home assistance. Sandra Bradley, however, encountered the most distressing of experiences when Jack became physically abusive, squeezing Sandra's arms and hand, bruising her and at one point breaking a bone in her hand. She hid Jack's actions for fear of what might happen to Jack, "I was afraid if I went to the emergency room that they would report it to the police .... so I didn't tell anybody." She explained further

He's always been so good to me, you know. And, that's why when he started being combative and cruel and bruising me, and he did, physically, both really physically and emotionally, and I hid that last summer from my sister and my son for months because I didn't want them to know that he was doing that. I, you know, because it wasn't Jack and I didn't want them to know. And, uh, he would grab my arms and shake me when I would try to give him his medicine. He would kick me. I have bruises everywhere. And, he broke my and squeezed it. Well, you can see.

***Spousal Informal Care Networks: "Giving me support."***

Support from other informal caregivers in spousal caregiving situations varied by who provided the support, what type of support was provided, and how often or to what extent support was offered. In four of the five situations, children provided support, but this varied greatly. Theo Vance had no surviving children and received support from his cousin and from Mary Margaret's sister. Only Reba Chatham received informal assistance from non-relatives. For a brief time, while her husband Roger was still able to walk alone in his neighborhood, neighbors reported his whereabouts to Reba intermittently. Throughout her care career, Reba's best friend of 35 years provided emotional support, even locating the MCU where Roger eventually moved. Reba recalled, "my best friend told me about this place." Table 5.3 displays who provided spousal caregivers' informal assistance and how often received.

**Table 5.3 Spousal Caregivers' Informal Assistance**

	<b>Reba Chatham</b>	<b>Annette Harrow</b>	<b>Allene Ballentine</b>	<b>Theo Vance</b>	<b>Sandra Bradley</b>
<b>Informal Assistance From Relatives</b>	Children, (Late in Career)	Children	Children	Cousin & Sister-in-Law	Son & Sister
	Occasionally	Upon Request	Only for Move To MCU	Each Relative, Twice Weekly	Upon Request
<b>Informal Assistance from Non-Relatives</b>	Neighbors Brief, Intermittent	None	None	None	None
	Best Friend, Routinely	None	None	None	None

In the range of support provided by children, Annette Harrow had the most readily available support. Her stateside children, both of whom at first lived out of state, would respond to Annette's telephone calls and conversations with her children with ready assistance, including a son traveling to assist with his father's supervision and later inviting his parents to reside with him, asking Annette, "Mommy I bought a house, do you want to come?" Annette continues to reside with a daughter who took in her parents and assisted often with monitoring. John's sister also assisted, by opening her home to Johns' visit and then traveling back to his home and staying for a short while. The assistance John's children provided with monitoring, his chief need, was very beneficial to Annette and provided a form of respite care.

Reba Chatham's experience with her children was different. Though she attempted to keep them apprised of their father's changes and condition, at first they were not at all receptive to the information, instead viewing Reba "as a complainer" and "a martyr." Reba "didn't have

any understanding and support there for a while,” knowing that her children were “in denial” and “not ready for” the conversations she needed to have with them. Still, it was not the “response” she expected of them. Reba also “didn’t have much [support] from friends because [she] ... wasn’t telling everybody.” After a time, however, all three children provided emotional support to their mother and assisted with several transitions. As previously noted, a daughter helped with taking away Roger’s driving privileges and later became a sounding board for Reba’s search for a care facility. All three children also assisted with transitioning their father to the MCU. At no point, however, did any of the children or friends assist with Roger’s daily care needs or provided respite care for their mother. Reba’s best friend of 35 years, however, did provide emotional support.

Allene Ballentine’s two sons provided even less direct support in the care of their father. Neither participated in any instrumental care, nor did they provide respite care for their mother. One son lived across the country. Another son, however, lived locally. “Right in the beginning” they advised Allene to place their father “in a home.” When it came time for Luke to move, one son assisted with move preparations and transfer to the MCU.

Sandra Bradley’s son and sister provided her respite from caregiving duties, allowing her breaks for showering and other personal time. The son also provided much-needed transportation, as Jack could no longer drive and Sandra did not drive at all due to a chronic health condition. Sandra’s sister’s emotional support became instrumental in the search and choice for Jack’s eventual residential care facility.

In the case of Theo and Mary Margaret Vance, help came from Mary Margaret’s sister, a mental health professional and Theo’s female cousin, who provided routine supervision respite care for Theo to “recharge the batteries ... enough to get away and do something or go do

nothing.” Mary Margaret’s sister proved key to Theo’s emotional support, as she had an educated understanding of her sister’s condition and Theo’s carework.

***Spousal Formal Care Services: “I went to outside help.”***

Three of five spousal caregivers used in-home aides to supplement their care. One used adult day services and an in-home aide concurrently. Only one spousal caregiver had no formal care assistance at home. Table 5.4 presents the type of formal care services spousal caregivers used and how it was used.

**Table 5.4 Spousal Caregivers’ Formal Care Services**

	<b>Reba Chatham</b>	<b>Annette Harrow</b>	<b>Allene Ballentine</b>	<b>Theo Vance</b>	<b>Sandra Bradley</b>
<b>In-Home Aide</b>	8-24 Hrs./Wk.	NU	Evenings Overnight	6-12 Hrs./Wk.	NU
<b>Adult Day Services</b>	Attempted Once	NU	Daily	NU	NU

NU= Not Utilized

Both Reba Chatham and Allene Ballentine went through a trial and error process of finding aides to assist them with their husbands’ care. Reba had difficulty locating an aide who was not only able to physically meet Roger’s needs, but meet her requirements for home safety and care cleanliness. For Allene, the search was related more to finding an aide with whom she could feel relaxed, eventually deciding for a male aide who continues to assist her at home after Luke’s move. Theo Vance also experienced difficulty with aides, but his problems were related to aides’ inability to deal with his wife’s combative behavior. In all three cases, aides worked multiple times weekly. Theo’s formal care assistance was for “two or three days a week for three or four hours.” He never used “anybody overnight.” The assistance allowed him to take care of personal business and appointments. Allene used an in-home aide nightly, someone who could lift Luke and administer nightly medications, allowing her to sleep and rest. Reba sought

formal care services when Roger's sexual advances became problematic. Aide assistance began with "four hours a day ... two days a week" and eventually increased to "three days a week and then six hours."

Allene Ballentine was the only spousal caregiver to use adult day services. Luke was a day participant at the MCU where he eventually resided, she explained how she "had to find a place to put him where he could go every day." Reba Chatham attempted to utilize an adult day program for Roger but found that the effort required to get Roger ready to leave was not worth the benefit of the respite time. Reba was also not able to find satisfactory caregiver support programs. She explained about the combination one adult day and caregiver support program she tried

It was just an hour. And, I was going to take him over there and go to the support group was what I was going to do. But, um, all the people were in wheelchairs and they were just sitting around there and they were just, and I thought no, this is not what he needs. The atmosphere wasn't good .... And the support group wasn't, because I had things to talk about, and there were only two of us there that day and that lady just had a friend .... So I knew I could not introduce anything I was dealing with 'cause that would not be appropriate. So, it wasn't going to work for me and him.

***Non-Spousal Carework: "You don't know what you're asking of me."***

In general, non-spousal carework was less extensive and physically laborious, but still emotionally intense. Though these caregivers provided little to no direct ADL assistance, they nonetheless assumed a variety of caregiving duties which they found to be difficult. Table 5.5 illustrates the care responsibilities of non-spousal caregivers. As noted earlier, none of these

primary caregivers lived with care recipients, which limited the labor intensity of their roles, though at the same time added some measure of travel time to their care burden. The emotional intensity of their care burden though was influenced by the omnipresent filter of negative family history. One daughter, Marsha Balfour found caregiving to be “very tiring” explaining, “You’ve got to figure out a way to deal with your own feelings.” Cecelia Beech, a daughter, recalled that caregiving and the attendant decisions were “very hard,” admitting that she is “dense about not catching on when Mother has new needs.” Dee Waterhouse just needs “to be in a certain frame of mind to see” her father. Like Dee, daughter Jilly Thornton and sister Pamela Hamm need to compartmentalize interactions with their care recipients. Jilly explains, “I don’t want to discontinue the way my life is.” Similarly, Pamela states that she does not “want to BE [her sister Theresa’s] life.

**Table 5.5 Non-Spousal Care Responsibilities**

		<b>Marsha Balfour</b>	<b>Cecelia Beech</b>	<b>Dee Waterhouse</b>	<b>Jilly Thornton</b>	<b>Pamela Hamm</b>
<b>ADL Care</b>	<b>Choosing Clothing</b>	X		NN		
<b>ADL Care</b>	<b>Bill Paying/Finances</b>	X	X	X	X	X
	<b>Grocery Shopping</b>	X				
	<b>Medical Appointments</b>	X	Some	X	X	X
	<b>General Transportation</b>	X	Little	Little	X	Some
<b>Medication Management</b>					X	

X= Care Task Performed

NN= Noted as Not Needed by Care Recipient

Dee Waterhouse’s father, Fred Grant, remained able to handle all his own ADL care.

Although the other four non-spousal care recipients routinely required varying and increasing

levels of ADL care, these duties were relegated to formal providers either in the home or in residential care. Much of non-spousal carework focused on IADL assistance, primarily providing oversight for finances, accompanying recipients to physician appointments, and transportation for medical appointments and shopping needs. All five caregivers provided some measure of assistance for these tasks. One daughter, Marsha Balfour, also provided transportation for adult day services. Medication oversight was provided by one daughter, Jilly Thornton. Even though Pamela Hamm's sister seemed to have difficulty monitoring her diabetic care routine, only telephone assistance was provided to Theresa Keller by Pamela.

Pamela recalled this instance

One day I got really mad because halfway, probably eight or nine months ago, she called me and she said, her blood sugar, and she said, 'Pamela, what's H I mean on my [blood sugar] monitor?' I said, 'That means it's so high it can't read it. What have you had?' It was like 11 o'clock in the morning. And, I said, what have you had?' [Theresa replied] 'Nothing! I haven't eaten anything!' [I] said, 'What have you had, have you had a Pepsi?' [Theresa said], One glass. I allowed myself one glass.' So, I said, 'Alright, you probably need to go to the ER.' [Theresa said], No! I won't go!' So I said, 'Alright, give yourself X Amount of insulin and I'll call you in half an hour.' ....I called her in half an Hour and it was lower. So.

By and large caregiving needs were met by a combination of arrangements including teamwork between the caregiver and other family members or a combination of formal care services.

Safety issues were a concern of non-spousal as well as spousal caregivers although the challenges were somewhat different. For example, where fall prevention was a strategy of spousal caregivers, the daughters of Janet Beech and Anne Littleton resorted to after-fall medical and formal care as a strategy. Anne Littleton's daughter Jilly remembered

It was every hour and she was falling down. She did hurt her back. Thankfully, she didn't break anything. She trapped herself in the stairwell. She let the dog off the leash and the dog ran away, you know, and the residents were just always trying to help her. And, when you would come into see her, her eyes were all dilated and she was sweaty, just completely out of her mind and I know it was because she had been taking too many medications. She was messing them all up. So, at that point somebody would come over to help her 3 times a day to give her her medications.

Dee Waterhouse had concerns about her father falling, however, her more direct concern was how her mother, Fred's ex-wife and roommate, would have to deal with the experience if Fred were to fall at home. The issue became a contributing factor to Fred's move out of his home to residential care. Dee explained

Something happens here in the middle of the night, somebody's going to find out and call you. And, in that apartment, my mother would have ... caused her major stress if she'd found, you know, if he'd fallen in the bathtub, what was she going to do. So, it's much better now.

Monitoring wandering behaviors generally was not a care task of non-spousal caregivers, who unlike spousal caregivers, were unavailable on a daily basis. For Dee Waterhouse, Jilly Thornton, and Pamela Hamm, after-the-fact formal care was the strategy used, and in each case,

concerns about wandering became contributing factors in moving decisions. Combativeness was not reported to be a behavioral issue by non-spousal care caregivers while recipients remained at home.

***Non-spousal Informal Care Networks: “What are you going to do about Mama?”***

Part of the intense emotional difficulty experienced by three non-spousal caregivers involved resentment toward other family members in regard to caregiving assistance. Three non-spousal caregivers also resented the frequency or lack of assistance received from siblings. Marsha Balfour explained “expectations” of her only sibling and subsequent disappointment, “My assumption had been that he would be helping me.” She does acknowledge that her brother, who lives locally, provides a small measure of emotional support. Marsha’s husband is supportive in this regard as well. As for sibling responsibility, Cecelia Beech said of her brother and only sibling, “He did not have any of the qualities of being responsible or being able to step up to the plate if he needed to no matter what.” Cecelia’s brother, who previously provided routine care assistance to their mother before his move out of state, provides little emotional support to Cecelia now with the exception of his agreeing with Cecelia about the care decisions she makes for their mother. Jilly Thornton, caregiver and youngest of four sisters, recognizes that each one has “very different perspectives” of their mother’s illness and needs. Her local eldest sister is “pretty much just out of the picture,” though this sister assisted briefly with medication management. The second oldest sister lives out of state and is not involved at all in their mother’s care, believing that their mother is “just faking it.” The sister closest in age to Jilly, her third sister and partner in some caregiving activities, is “too wonderful” and “overly protective” of their mother, so “sometimes [they] don’t see eye-to-eye on things related to” their

mother Anne. This sister helped Jilly make the decision for their mother Anne's move, toured NHs with their mother, and assisted with medication management prior to the move.

A sibling caregiver deeply resented being the only one left in her family to become the caregiver now and in the past for her sister. Pamela Hamm's strong reaction to "ALL THESE FAMILY MEMBERS" requiring oversight, including her sister Theresa Keller, was: "I CAN'T STAND IT!" Pamela said, "I just did the best [I] could do and ... had to let some of it go."

Only one non-spousal caregiver, Dee Waterhouse, seemed to have no network relationship difficulties in meeting her father Fred Grant's needs. Dee had two care partners. Her mother, Fred's ex-wife and roommate, provided much of the needed transportation, taking Fred to and from his adult day program and to buy groceries and even driving him to and from Dee's home to have supper. Dee's mother also provided daily medication management for Fred. Dee provided transportation and oversight of Fred's medical care. Dee explained the arrangement that she had with her mother for meeting her father's needs

I took him to the doctor. I did the doctor stuff, prescriptions, driving stuff .... [Dee's mother would] take him to the grocery store with her if she didn't need much. She'd take him around .... [she would] help us by making sure he had his medicine .... We'd have him over for dinner and my mother would drive him over and after dinner, drive him home. So, I wasn't even doing that.

Dee's out-of-state sister assisted with the decision for Fred to move out of his home and the selection of the AL. Table 5.6 exhibits the type and frequency of assistance provided by other informal caregivers in non-spousal situations.

**Table 5.6 Assistance Provided by Other Informal Caregivers**

<b>Marsha Balfour</b>	<b>Cecelia Beech</b>	<b>Dee Waterhouse</b>	<b>Jilly Thornton</b>	<b>Pamela Hamm</b>
<u>Husband:</u> Emotional Support	<u>Brother:</u> Agrees on Care Decisions for Mother	<u>Mother:</u> Routine Transportation Assistance, Daily Medication Management  <u>Sister:</u> Located MCU	<u>Eldest Sister:</u> Brief Medication Management Assistance  <u>Third Sister:</u> Medication Management, Toured NHs, Assisted with Move Decision	None

***Non-Spousal Formal Care Services: “I got a part-time caregiver for her.”***

Three non-spousal caregivers made a number of formal care arrangements to assist them with caregiving. In each instance, private payment was made for these arrangements. Table 5.7 shows the formal care services arranged for by non-spousal caregivers. Services for recipients were added not only as recipients’ care needs increased, but, as in the cases of both Marsha Balfour’s mother and Dee Waterhouse’s father, as caregivers sought activity outlets for them. Marsha recalled adding formal services: “When I became really concerned [about my mother] I ... got the home care in the morning. As I became increasingly concerned, I began to get more and more things over there, and you know she would get ok.” Her mother, Catherine Dunn, resided in IL at a different residential LTC location then, only later moving for AL services at the study site. After moving to AL, Catherine received increasing amounts of formal care up to the maximum available from the AL facility, and in addition, received home health aides from external sources for morning and evening care. Marsha also enrolled her mother in an adult day program three times weekly for “activities.”

Cecelia Beech first used formal in-home care and eventually AL for her mother Janet Chester who lived several hours away. While at home, an aide came three times a week for 15 total hours weekly, which over the course of about 18 months, increased to 25 total weekly hours spanning five days of care. In the beginning, Fred Grant attended an adult day program twice-weekly. According to his daughter Dee Waterhouse, “it gave him something to do. It got him out of the apartment and all that.” Neither Jilly Thornton nor Pamela Hamm utilized formal services.

**Table 5.7 Formal Care Services in Non-Spousal Situations**

	<b>Marsha Balfour</b>	<b>Cecelia Beech</b>	<b>Dee Waterhouse</b>	<b>Jill Thornton</b>	<b>Pamela Hamm</b>
<b>In-Home Aide</b>	AM PM	15-25 Hrs./Wk.	NU	NU	NU
<b>Adult Day Services</b>	3X Weekly	NU	2X Weekly	NU	NU

NU= Not Utilized

### *Summary*

As this chapter demonstrates, distinct differences exist between spousal and non-spousal caregivers. While caregiving responsibility elicits strong emotional response in all caregivers, the nature of that response is dissimilar. Spousal caregivers’ identities are positively bound to their recipients and they immerse themselves in the necessary care tasks with dedication. Non-spousal caregivers, on the other hand, experience an upheaval of emotional distress related to poor family relationships with their care recipients or other family members involved in caregiving scenarios. Their approach to caregiving approach is tendered with reluctance and resentment. How the two groups engage in caregiving tasks and the duties they assume also varies between the two groups.

Spousal caregivers assume ADL, IADL, and supervisory caregiving tasks as they are necessary only ceding them to others after experiencing difficulty maintaining an ability to continue at the level needed by the care recipient. Additionally, all spousal caregivers live where they perform their carework, unlike all non-spousal caregivers. While non-spousal caregivers also reach limitations for care, overall, their care tasks include virtually no routine ADL or supervisory chores and are primarily limited to IADL duties. Issues of caregiver burden, that is, the labor of caregiving, the internalized response to that work, and the subsequent changes in caregivers' environments because of these factors, differ widely between spousal and non-spousal caregivers and are discussed in depth in the following chapter.

## **CHAPTER 6**

### **MAKING THE DECISION**

This chapter examines in greater detail the decision-making process of moves to either AL or NH care settings and specifically to MCUs. It begins with an examination of the multi-level factors that affect decision-making, particularly the role of care burden and how it is experienced and perceived across care situations. The chapter next examines who the key decision-makers are in initial moves from the home and in intra-facility moves and how and why particular care settings are selected. The chapter ends with a discussion of the outcomes of moving decisions for caregivers and care recipients.

#### *The Process of Decision-Making*

Caregiving experiences played a significant role in caregiving decisions. In each of the ten situations reported on here, accumulating amounts and types of carework responsibilities created increasing levels of stress, eventually affecting each caregiver's ability to continue at the same level and deciding a move to a different care setting was necessary. This stress, commonly referred to as caregiver burden, was experienced chiefly in three ways: through the physical acts of caregiving, associated emotional responses to carework or care relationship, and the subsequent changes in caregivers' lifestyles. Caregiver thresholds for levels of burden varied and greatly impacted the timing of moves from initial care settings, further illustrating the complexity and interactive nature of the multiple factors influencing decision-making. Although this analysis indicates that burden is the key factor driving moving decisions, additional factors that affect the process of decision-making, including options for moving and knowledge of dementia, also are evident.

As noted in previous sections, five care recipients moved directly into MCUs, either AL or NH. The other five care recipients first moved to a general AL or NH population. The choice between these scenarios, which will be discussed in greater detail in the section addressing site selection, also is influenced by multiple, multi-level factors.

### ***The Concept of Care Burden***

Perceptions of caregiving burden emerging from the study's analysis, closely parallel Aneshensel and colleagues' (1995) categories of caregiving stress in three distinct areas of burden that Mennino and associates (2005) refer to as "spheres." Constituting the first sphere of burden is engagement in carework, a combination of pervasive and unrelenting tasks, often laborious and performed repetitively with some degree of isolation over a period of time. At some point in the care career, differing for each caregiver according to individual sensitivities and thresholds, the experience of carework generates an emotional response that can be thought of as the second sphere of burden. The development of the third sphere of burden evolves out of the caregiver's effort to obtain relief and restore some sense of stability from the challenge and growing pressure of the combined carework and response found in the first two spheres. In this third sphere, the caregiver engages in lifestyle changes seemingly to combat the negative effects of physical and emotional stress that are not wholly positive, that in the end, detract from the caregiver's overall quality of life experiences. For caregivers, this is the point when decision-making to move the care recipient to an alternative care site occurs.

### ***Factors Influencing Real and Perceived Burden***

Though experienced by all, these spheres of burden differ across the ten caregiving situations and according to a number of interactive factors. For the most part, factors are at the individual level and include characteristics of caregivers and recipients, nature of the relationship

between caregiver and care recipient, living situation , availability of other support (formal and informal), features of the home environment, and financial resources. A more detailed account of these interrelated factors and their effect on burden and decision-making is provided below.

*Characteristics of the Care Recipient.* As would be expected, a care receiver's health conditions and functional status, including the specific dementia diagnoses, degree of cognitive and physical impairment, and presence of other chronic conditions had significant influence on the level and type of caregiver burden. In general, those with greater range and degree of need created the highest level of burden. For example, John Harrow, who had no ADL needs, was physically active and had behavior problems (aggression and wandering) directly associated with his type of dementia (VaD). Together, these attributes created significant supervision difficulties for his spousal caregiver. Most care recipients exhibited wandering or other behaviors that required constant monitoring to ensure safety. Those who also had heavy ADL needs, such as Roger Chatham, compounded their caregivers' burden. Roger's routine sexual advances to his wife Reba, after she no longer desired to engage in sexual activity with him created even more stress for Reba, who had to change not only how she provided his ADL care, but how she related to him emotionally. Few recipients were able to provide their own ADL care, and all required some form of IADL assistance. Other care recipients, such as Theresa Keller, who frequently did not comply with her diabetic treatment regimen, had issues related to other chronic conditions which affected her sister Pamela's care burden in different ways.

Additional care problems arose from recipient values, particularly related to preserving some degree of independence. One spousal recipient insisted on making home repairs though he was unable to complete such tasks and another refused to take medications from anyone but his wife. Other recipients insisted on driving after cognitive impairments caused skill deficits. All

these instances required caregivers to engage in stressful problem-solving and added to their carework responsibilities. This was also the case with IADL care tasks though both spousal and non-spousal caregivers participated in this type of task.

Other recipient characteristics had habits and interests such as smoking and cooking that were potentially hazardous and created safety issues when they were unsupervised. Both Mary Margaret Vance and Fred Grant enjoyed cooking, but sometimes left appliances turned on. Theresa Keller was a heavy smoker whose clothes and bedding, over time, became riddled with holes.

***Relationship between the Caregiver and Care Recipient.*** The nature of the relationship between caregiver and care recipient also had a significant influence on the level and type of burden experienced by caregivers. Differences between spousal and non-spousal caregivers were particularly evident as spousal caregivers were more heavily impacted by recipients' care requirements due to the nature of their relationship and living arrangement and by the fact that spousal caregivers were heavily involved in ADL care, unlike non-spousal caregivers.

In this study, differing values regarding the caregiver role also distinguished spousal caregivers from non-spousal caregivers and was another factor that contributed to differences observed between these groups with regard to caregiver burden. All spousal caregivers were found to uniformly place high value on their marital relationships. Each experienced a strong sense of duty to personally meet their spouses' changing needs until they reached burden limitations related to physical ability, mental stress, or personal safety.

Non-spousal caregiving relationships, with the exception of a pair of siblings, were parent (four mothers and one father)-daughter. Caregivers all expressed varying degrees of attachment to their recipients due to unresolved family issues developed over the life course ranging from

little affinity and empathy to being greatly conflicted and affected. Old family business had great, if not deleterious effects, on how they carried out their caregiving duties, when they reached limits for continuing, and eventually made decisions for moves. Still, all took on the caregiver role and met an obligation with some sense of responsibility. As a whole, non-spousal caregivers sought earlier relief for fewer types of burden with decisions for moves. At the same time, their recipients' prior living situations were much more precarious, if not dangerous at times, because of the overall lesser degree of supervision they received compared to spousal care recipients.

***Living Situation.*** Spousal caregivers and their recipients occupied the same living space, significantly affecting the amount of labor, vigilance, and lifestyle disruption caregivers experienced providing less opportunity for separation from the caregiving experience and more subsequent burden. In the situation of Annette and John Harrow, the spousal pair later lived with a daughter in her home which somewhat reduced the burden on the Annette because the daughter was able to take on the role of monitoring nighttime wandering. None of the non-spousal caregivers lived with their recipients and one daughter lived in a different state from her recipient mother. As a result, non-spousal caregivers' scope of vigilance and labor was more narrow and intermittent due in large part to separation in the living situation. In the case Fred Grant, who resided with his ex-wife who provided considerable assistance, the burden of his caregiving daughter was lessened.

***Caregiver Factors.*** Factors related to caregivers, including personal characteristics, employment status, and health conditions, encompassed a broad range of influences on spheres of burden. With regard to paid work, three among spousal caregivers encountered conflict between carework and paid work and subsequently elected to give up paid work in favor of

becoming full-time caregivers. Three non-spousal caregivers continued to work, one of whom also had a young child at home adding to their levels of stress.

Gender also affected care burden, as shown in the shifting of established patterns of household responsibilities that previously aligned with traditional gender roles. In the case of one wife, Reba Chatham, a first-time leadership role was assumed that entailed new experiences of decision-making. In another instance, husband Theo Vance, gradually assumed tasks such as meal preparation, typically carried out by his wife. In Reba's case, her expanding role brought her satisfaction, but for Theo, engaging in traditional female duties caused added stress.

Carework, as noted in an earlier chapter, is typically a female role (Calasanti & Slevin, 2001). Men who are unaccustomed to carrying out tasks associated with women's roles may experience some emotional response, or stress, with this responsibility, adding to their sense of burden (Calasanti & Bowen, 2006).

Values and beliefs shaped how some spousal caregivers, females in particular, approached responsibility. Faithfulness to marriage vows, faith in God, and responsibility that two wives attributed to their Southern upbringings were three themes that emerged as tenets directing them to take care of their husbands, exclusive of the love and devotion that they also felt for them. Annette Harrow noted: "I accept whatever God sends to me. I pray about it every day." Similarly, Reba added: "Well, first of all you go back to prayer. I prayed about what to do." Reba also believed that her background was influential. Sandra Bradley likewise identified strongly with her South Georgia rearing noting a custom of wives to put husbands before themselves. Sandra explained: "I just, I have to care for him. He's first .... He's got me wrapped around his little finger."

Some caregivers' physical attributes in relation to their recipients, such as size and strength, contributed to difficulty in carrying out care tasks. This was true in the case of Sandra Bradley, whose husband Jack towered above her. Several caregivers experienced health problems ranging from infections and minor illnesses to more serious ailments such as heart problems and cancer that cumulatively, but directly in some cases, impacted the timing for moving decisions. An example is Theo Vance, who began to consider what would happen to his wife if his heart disease or cancer became unmanageable and he was no able to care for her. Caregivers, such as Sandra Bradley, had difficulty managing care loads and remaining attentive to active recipients on less sleep. Other caregivers reported eating poorly and engaging in less physical exercise, types of stress that impacted their health situations, and contributed to their overall levels of burden.

Generalized or specific knowledge of dementia differed greatly among caregivers. Most had some concept of or prior experience with dementia, having either sought or received information through a number of sources, including a range of media outlets or personal contact with professionals, family members, or acquaintances. Some caregivers questioned recipients' professional diagnoses, others delved deeply to learn more about the established diagnosis, and a few eschewed opportunities to learn more either because additional information was too painful to consider or the need to hope for an outcome that would not require them to experience their recipients' decline. Altogether, knowledge affected how caregivers approached their carework, made sense of their experiences, and dealt with the subsequent impact. Caregivers who achieved some understanding of typical dementia behaviors were able to attribute problem behaviors to the dementia, rather than the recipient, and adjust their caregiving techniques to achieve greater success with less stress and make adjustments to care settings to increase recipient safety.

*Support from Others.* Caregivers received varying amounts of support from informal and formal sources. Informal sources included family members and friends, who in some cases assisted caregivers with care tasks or provided emotional support or assistance with site selection. Encouragement for decision-making was a specific area in which caregivers received support from family and friends. Informal care support reduced the burden of some primary caregivers and enabled some to engage in longer care careers and at the same time delay decision-making for moves. The daily informal support received by Dee Waterhouse from her mother (and father's ex-wife) was instrumental in delaying her father's move as was the support received by Annette Harrow from her daughter and son. Annette and her husband John's situation that included living first with their son and later with their daughter may have been influenced in some part by racial or cultural values linked with their heritage in their Caribbean country of origin, Tobago.

Use of formal support sources, such as in-home aides or adult day services, was dependent on financial resources as well as fit to recipients' needs and varied in availability and use according to relationship type, living situation, or care recipient characteristics. Spousal caregivers Reba Chatham and Allene Ballentine had difficulty finding in-home aides of adequate size and strength to meet their husband's ADL needs. For both, keeping their husbands at home with them as long as possible was a primary goal. Finding formal support to adequately meet those care needs was essential to them meeting that goal. A lack of formal sources negatively impacted recipients' abilities to remain in the prior living situation as well, and created a greater care load for the caregiver and a sense of greater emotional pressure, both of which related to timing for decision-making for moves. Jilly Thornton had no formal care arrangement for her mother Anne, who lived alone. Anne's increasingly erratic behavior, confusion, and

susceptibility to falls, as well as her need for three-times daily medication management created strong pressure for Jilly, who is also a small business owner and mother of a small child, to make a move decision.

***Physical Environment of Living Situation.*** Over time, recipients' physical environments began to less adequately support their safety and well-being. Likewise, caregivers experienced increased difficulty with aspects of care as environmental fit decreased along with increasing physical work load and vigilance, as well as stress levels. Aspects of the environment, such as stairs, floor plan design, and type of door locks, related to falls, and elopement risk, contributing to the vulnerability of recipients as well as care burden.

***Finances.*** Financial resources of both caregiver and recipient played an important role in the ability to access formal care services, make lifestyle adjustments for the benefits of both caregiver and receiver, and delay decisions for moves. Caregivers able to access formal care reduced the physical burden of care tasks and some measure of their subsequent emotional stress. Financial resources provided other options including the ability of caregivers to exercise choice, such as those caregivers who gave up paid work environment for full-time care careers or those who maintained the ability to pursue personal interests or receive respite. Financial resources also provided some influence on the timing for decisions for moves and well as the locations eventually chosen.

### ***Options for Moves***

Aside from financial considerations, options for moves were primarily limited by the number and scope of recipients' ADL needs and characteristics discussed in a previous section. The same needs and characteristics that made recipients less likely to remain in the home also limited the type of residential LTC that was appropriate to meet those needs and reduced the

options that were available to caregivers when making move decisions. Though only four caregivers initially sought the MCU option, all six other caregivers who initially chose an intermediary location were confronted by administrators with their recipients' assessments for the need for specialized care in an MCU. Advice for transfer from intermediary settings to an MCU came from within days of a move to no more than five months after a move. As will be discussed in the section on site selection, a caregiver's attitude toward the appropriateness and desirability of a potential care setting in certain cases influenced the timing of moves, leading to earlier moves than might otherwise would have occurred. Each of these cases involved moves to AL.

### ***Knowledge of Dementia***

Care recipients' knowledge of dementia also affected their ability to acknowledge a future need for increased recipient care over time, including the potential for making decisions for moves, which in some cases influenced the timing of moves. As noted above, the level of knowledge varied across caregivers, and how caregivers made use of this knowledge in the timing of their decisions for moves varied as well. For example, Theo Vance became well-educated about his wife's diagnosis (AD) through personal research and her physicians. As a result, he had some expectation of the typical course and features of AD. As her illness progressed, he understood that her ability to remain safely at home was becoming increasingly challenged and he used this information to help him make an informed decision about her placement in a NH MCU. Marsha Balfour, on the other hand, though having had the benefit of some degree of knowledge of dementia, was not able to understand the relevance of that knowledge to her mother Catherine Dunn's situation. After Marsha chose AL care to meet her mother's mounting needs, she became quite angry and shocked upon learning the administrator's

evaluation of her mother within months, which required Catherine to transfer to the MCU or move out.

### ***Summary***

Caregiving experiences played a substantial role in decisions for moves to residential LTC facilities in large part because of their effect on caregiver burden. Burden was found to be a product of both carework and the emotional experiences associated with caregiving. Recipients' ADL and supervision needs and caregivers' abilities to meet those intersected in complex ways creating not just varying amounts of stress, but different types. Long-married spousal caregivers experiences were intense because of both the nature of their relationship to their recipient and because they lived full-time in the care setting. Experiences of non-spousal caregivers were intense because of enduring family baggage. Support of differing types, emotional and instrumental, and sources, formal and informal, had the potential for not only reducing caregiver stress, but delaying the timing of caregivers' decisions for moves to memory care. But the physical environment of the prior living arrangement created some amount of difficulty and stress as home features, such stairs and floor plans, could create safety hazards for recipients and add to caregiver burden experiences. Other problems that occurred and that had the potential for affecting the timing of decisions were caregiver characteristics, such as illnesses or employment. Finances were important not only to the ability to access formal care while the recipient was still in the home, but choices caregivers could make about the type of residential LTC. Finally, knowledge of dementia played a varying role in decision-making with some caregivers accessing and utilizing what they learned to make informed decisions and others less so or not at all.

### ***Who Made the Decision***

This section examines who is involved in making moving decisions regarding initial moves from the home, and in five cases, subsequent intra- and inter-facility moves to MCUs. As previously noted, the ten caregiving situations varied depending on whether moves were made directly from the care recipients' home into facility MCUs (five situations) or whether prior intermediary moves to the general AL or NH populations followed by subsequent moves to MCUs occurred. The process of decision-making for all initial moves (whether or not directly to an MCU) differed in multiple ways from decisions regarding transfers from general AL or NH populations to MCUs. The type of decision-maker varied as well. Because of these differences, the two types of decisions will be addressed separately in this section.

#### ***Initial Moves***

In all caregiving situations, the primary caregivers were also the primary decision-makers regarding initial moves from the home. Only one caregiver, Pamela Hamm, who cared for her sister, ostensibly made the decision alone. In other caregiving situations, at least one other person was involved.

***Spousal Caregivers and Shared Decision-Making.*** Table 6.1 shows the types of individuals involved in spousal caregiving situations. In spousal situations, physician influence provided the strongest sway in decision-making, with the exception of Allene Ballentine, who voiced that move matters were not the doctors' decision. Physicians in the other situations were credited with providing credible and influential opinions about the use of residential LTC and the need for a move. In two instances, Reba Chatham and Theo Vance, physicians consistently provided information about potential recipient outcomes over an extended period of time that had a direct effect on those caregivers' more gradual move decisions. For two other spousal

caregivers, Annette Harrow, whose husband John's wandering posed great risk to him, and Sandra Bradley, whose husband's aggressive physical behavior posed great risk to her, caregiving situations had escalated to a point where physicians in these situations urged immediate placement in residential LTC.

**Table 6.1 Spousal Secondary Decision-Makers in Initial Moves**

<b>Others Sharing Spousal Decision-Making</b>	<b>Reba Chatham</b>	<b>Annette Harrow</b>	<b>Allene Ballentine</b>	<b>Theo Vance</b>	<b>Sandra Bradley</b>
<b>Children</b>		X	X	NLC	X
<b>Other Family</b>				X	X
<b>Friend, Neighbor</b>	X				
<b>Physician</b>	X	X		X	X
<b>Other Professional</b>				X	

NLC=No Living Children

In spousal situations, physician influence provided the strongest sway in decision-making, with the exception of Allene Ballentine, who voiced that move matters were not the doctors' decision. Physicians in the other situations were credited with providing credible and influential opinions about the use of residential LTC and the need for a move. In two instances, Reba Chatham and Theo Vance, physicians consistently provided information about potential recipient outcomes over an extended period of time that had a direct effect on those caregivers' more gradual move decisions. For two other spousal caregivers, Annette Harrow, whose husband John's wandering posed great risk to him, and Sandra Bradley, whose husband's aggressive physical behavior posed great risk to her, caregiving situations had escalated to a point where physicians in these situations urged immediate placement in residential LTC.

Children, to a lesser degree provide support for move decisions ranging from none to eliciting move-supportive opinions to supplying tacit agreement and support during the process and for moves. Reba Chatham's three children were not at all involved in her decision to move

Roger, most likely because their support came late in her care career. A daughter learned of the decision only after Reba began considering sites. Reba confirmed her decision to all three of her children only after she made the deposit to the chosen site and the move was imminent. Early in their father's illness, Allene Ballentine's two sons matter-of-factly urged their mother to place their father in residential LTC. Two of Annette Harrow's stateside children and Sandra Bradley's only child all provided support for their mothers' decisions for moves, with Sandra's son being most vocal about his mother's need to decide because of the risk to her personal safety.

Others involved in move decisions including other family, found in two cases, Theo Vance and Sandra Bradley. Theo's wife's sister and Sandra's sister both provided support for decision-making. Only Reba Chatham received move support from a friend and Theo, who utilized a wide array of information sources in his decision-making, was the only spousal caregiver acknowledging the role of other professionals. Overall, Theo, who had no children, had the greatest secondary support for decision-making. Allene Ballentine, who coincidentally made use of the greatest amount of in-home formal care utilized the least amount of secondary support for making a decision for her husband's move.

*Non-Spousal Caregivers and Others Sharing in Decision-Making.* Among non-spousal caregivers, fewer other individuals were involved in move decisions than was the case for spousal caregivers. Other family members and other professionals provided the most support, but even this was found in limited amounts. Table 6.2 illustrates those involved in non-spousal decisions for initial moves.

**Table 6.2 Non-Spousal Secondary Decision-Makers in Initial Moves**

<b>Others Sharing Non-Spousal Decision-Making</b>	<b>Marsha Balfour</b>	<b>Cecelia Beech</b>	<b>Dee Waterhouse</b>	<b>Jilly Thornton</b>	<b>Pamela Hamm</b>
<b>Children</b>	NC	X			
<b>Sibling</b>			X	X	
<b>Other Family</b>			X		
<b>Physician</b>		X			
<b>Other Professional</b>	X	X			

NC=No Children

Both Dee Waterhouse and Jilly Thornton had cooperative relationships with their sisters in both caregiving and decision-making. Dee's and Jilly's sisters provided sustained assistance and their roles in the process were freely acknowledged. Dee's mother, who was divorced from her husband but shared a home with him and helped care for him, also played a part, as Dee consulted her and Dee's decision to move her father was made with her mother's support. Both Marsha Balfour and Cecelia Beech utilized other care professionals in their processes for confirmation of their move decisions. In Cecelia's case, in which two care professionals influenced the move decision, one being her mother's physician, who made clear to Cecelia the requirement for full-time care for her mother, interpreted as residential LTC, at the time of hospital discharge. Unlike spousal caregivers, most of whom heavily relied on physician opinions, Cecelia was the only non-spousal caregiver influenced by this type of professional. Cecelia's use may be due in part to her earlier attempts to forge a relationship with her mother's physician to both receive and share information about her condition. Having initiated a cooperative relationship with the physician, it seems reasonable that she would continue to utilize this relationship.

Children were of little influence for non-spousal caregivers' decisions. Only Cecelia Beech's son provided brief emotional support during the time that she evaluated how to proceed.

However, Cecelia's son was of college age, soon to move several states away. There were other, related reasons for this category being less influential for move decisions. Jilly Thornton's only child is quite young and therefore would most likely have been of little support in decision-making. Marsha Balfour had no children to participate and Pamela Hamm's four children, all adults, and some residing out of the country, were not acknowledged to be involved in caregiving and so most likely would not have participated in making move decisions.

Overall, among non-spousal caregivers, Cecelia Beech received the most support and influence from secondary decision-makers for the move decision. Pamela Hamm, an RN, received the least assistance. Her independent decision-making was most likely due to two types of influences not relevant to other non-spousal caregivers: her professional experiences in the hospital setting, which provided her knowledge of and ready access to LTC settings, and her extensive background as a care provider to other family members, which contributed to her certainty about the need for the move.

As a whole, spousal caregivers compared to non-spousal caregivers, received, and likely needed, greater support for their decision-making. As made clear earlier, all were significantly more involved in and emotionally committed to their carework, which made reaching the decision to move more stressful. Moreover, the degree of burden they experienced led others to encourage, and in some cases, prod them to make this important decision.

### ***Intra- and Inter-facility Moves to Memory Care Units***

In this group of recipients various events occurred that prompted administrators to require moves from the general populations of both AL and NH to MCUs. These included four intra-facility moves, one inter-facility move (i.e. move from the general AL population in one AL to

MCU in the study site AL). Table 6.3 shows the recipient factors contributing to moves according to whether moves occurred in ALs or NHs.

**Table 6.3 Factors Influencing Recipients' Moves to MCUs in AL and NH Settings**

	<b>Catherine Dunn</b>	<b>Janet Chester</b>	<b>John Harrow</b>	<b>Anne Littleton</b>	<b>Theresa Keller</b>
<b>Recipients' Locations</b>	<b>AL</b>	<b>AL</b>	<b>NH</b>	<b>NH</b>	<b>NH</b>
<b>Recipients' Characteristics Influencing Moves to MCUs</b>	ADL Deficits	ADL Deficits	Wandering and Combative Behaviors	Wandering and Combative Behaviors	Wandering Behaviors

In the two ADL cases, moves to MCUs were based on recipients' increased ADL needs deemed to be beyond the scope of care available in the AL populations. In all of the NH moves to MCUs, wandering behaviors were involved. In two of these, combative behaviors also were a factor. As would be expected in NHs, which typically provide higher levels of ADL care compared to ALF, ADL care needs were not a precipitating factor.

Caregivers received and incorporated news of transfer decisions differently. In two of the transfers, the caregivers (both daughters) reported being deeply shocked and seemingly completely surprised by the AL administrators' evaluations and decisions, though both of their mothers had great difficulty successfully living in AL and had numerous ADL deficits requiring additional care. At the time of the interview, some perspective had been gained over time about their mothers' situations, which were somewhat similar. Both daughters had come to accept the administrators' decisions, which likely was due in some part to their recipients' combination of confusion and high need of ADL care. Both daughters also acknowledged some understanding of the further decline that could be anticipated for their mothers over the course of their disease processes that was of great concern, unlike any of the other four caregivers.

In the other three situations (a wife, a daughter and a sister), caregivers reported accepting the decisions more matter-of-factly. Three, however, expressed some measure of disappointment at the time of interview that their recipients were living in the NH's MCU, believing that they no longer needed the supervision that led to the transfers. All three of these situations were in the NH. These caregivers felt various levels of attachments to their recipients, but their recipients, were all verbally higher functioning than other NH MCU residents. In addition, one of these recipients, John Harrow, had since undergone a leg amputation and his wife believed his use of a wheel chair prevented him from being an elopement risk.

The remaining transfer situation (AL) of a recipient of a daughter, not only was accepted matter-of-factly, but continued to be accepted at the time of the interview. This daughter may have felt less distress about her father's transfer and subsequent living arrangement because she felt some emotional detachment to him and retained some amount of anger to him for events occurring in the family decades earlier.

### *Site Selection*

Decisions for the AL or NH sites were based on numerous factors relative to caregiver and recipient, as well as influences related to the prospective site and the community. The following sections provide an overview of important elements of the overall selection process and detailed information of individual-, facility-, and community-level factors.

### *Selection Process Overview*

Caregivers' decisions fell into two distinct groups, initial decisions for moves into MCUs and initial decisions for intermediary moves to the general AL and NH populations. Sites considered during the selection process were based on caregivers' decisions for moves either to MCUs or other site settings. Both AL and NH locations were utilized for both types of moves

and many multi-level factors intersected to influence these choices. The following sections elaborate in greater detail on the many factors important to study participants during the site selection process.

### ***Factors Influencing Selection***

Caregivers were influenced by a host of individual-, facility-, and community level factors intersecting in a variety of ways. Chief among them was financial resources. However, other factors were important as well, not the least of which were recipients' characteristics and care needs. Additional features such as location, size, programming, secure boundaries, or affinity to décor among others were also significant. Timing for move decisions and the amount of time taken to deliberate for a decision were central to not just when decisions were made, but how and these factors varied widely. The following sections provide more detail about these factors from the perspectives of various levels.

***Individual-Level Factors.*** Caregivers' choices were very personal and were firmly linked to recipient characteristics, their own preferences and values, and financial resources. How caregivers chose according to these factors was further complicated by options available within the AL and NH sites either for a general population setting or a specialized setting, the MCU.

One of the main considerations on which caregivers reflected was recipients' characteristics, including ADL, IADL, behavior supervision, and medication management care needs. Awareness that recipient-changed characteristics and needs surpassed suitability of the living arrangement was an impetus for changing the living arrangement in all ten caregiving situations and finding a setting that could appropriately meet those needs was paramount. One of the strongest recipient characteristics that required addressing was behavior, both wandering and

combativeness, presenting safety issues not only for recipients, but in some cases, for caregivers or others. The other strongest care concerns were associated with heavy ADL needs which were becoming difficult to meet for four of five spousal caregivers residing with recipients and four of five non-spousal recipients who received varying levels of assistance. Caregivers believed that AL or NH LTC could meet all those needs. These varying needs determined the type of site required, thus interacting with facility-level factors noted below. For example, caregivers, Theo Vance and Sandra Bradley, initially selected MCUs from other types of care focusing on how a secure unit would meet their recipients' high need for supervision. Other caregivers, Reba Chatham and Allene Ballentine, chose MCUs initially because of the wide encompassing care that would meet all their recipients' needs. Other caregivers chose general AL or NH settings because their recipients' needs seemed to revolve more around ADL care, as both Marsha Balfour and Jilly Thornton believed.

Caregivers expressed a wide number of views about the sites they considered. Some of these were related to values held about the nature of NH versus AL care. Both Marsha Balfour and Cecelia Beech expressed opinions against NH use, eliminating them altogether from consideration for residential LTC. Quality of care was a very important issue, but did not always figure highest in site selection. Both Reba Chatham and Marsha Balfour made their choices with reputation of care in mind. Pamela Hamm, however, accepted that her site choice did not have the stellar reputation that she desired, but it that it nonetheless met her needs given the acknowledged financial constraints. Her attitude about her sister-recipient may have born some influence over her use of the NH site, though other factors such as convenience were important as Pamela also is employed.

By far the most important factor to whether an AL or NH site was chosen was related to finances. Those with sufficient financial ability chose AL settings. Marsha admitted that her mother would not have been able to afford an AL setting without the financial advantage of second husband's estate. Dee Waterhouse expressed some degree of satisfaction, if not smugness, over the ability to place her father in AL, acknowledging that not everyone can "afford places like this and are actually bathing them and changing them and everything." If some caregivers' choices were supported by financial resources, others were limited by them. All users of NH care reported being unable to consider any other type of site because of financial constraint. Theo Vance's, Sandra Bradley's, and Pamela Hamm's recipients made use of Georgia Qualified Income Trusts. Both Annette Harrow's and Jilly Thornton's recipients also had low income limiting them to NH use. Pamela expressed hope that changes in Georgia's laws for LTC compensation would allow her to move her sister to an AL property in the future. Jilly, too, believed that her mother would do better in an AL setting.

Class values emerged from the study through several of the study's participants. Allene Ballentine voiced how some other locations she had toured prior to making her selection were dismissed: "We looked at two places. They were not for us. (laughs) One looked like Mr. Rogers neighborhood. I said, 'Oh God!' And the other, they were so pushy, it was offensive."

Privacy was a value for both Allene and Marsha Balfour, who insisted that their recipients would not be able to share bathrooms with other residents. In the NH, all units in both the general population and the MCU were designed to be shared, both bedroom and bathroom. Cecelia Beech had a related, but very different attitude about her choice. Her site investigation had tended toward more casual "bed and breakfast" versus "grand hotel" upscale settings because of her knowledge of her mother's previous discomfort in such surroundings.

Caregivers' values regarding programming and services as important quality components influenced sited selection for their recipients. Marsha Balfour, Cecelia Beech, and Dee Waterhouse appreciated the AL's activities and guided programming. Sandra Bailey specifically desired her husband to have both occupational and physical therapy to improve his quality of life. The NH she selected could accommodate her request and she was pleased that the MCU would offer dementia-specific programming. Both Sandra and Reba Chatham also like the level and amount of interaction with residents from the NH and AL staffs and administrators, each believing that their recipients were receiving kind and attentive care in their respectively-chosen sites.

Seven caregivers solicited or received opinions from trusted sources about the kind of site to choose. Annette Harrow and Marsha Balfour both sought opinions about where residential LTC could be provided for their recipients. Annette asked a neighbor about NHs to locate the site she subsequently chose. Marsha was influenced by a care agency owner and as a result, selected the only site she toured (AL) following the professional's recommendation. Reba Chatham, Cecelia Beech, Dee Waterhouse, Sandra Bradley, and Jilly Thornton all received recommendations from others for the sites they eventually chose. Allene Ballentine, Theo Vance, and Pamela Hamm made site selections independent of others' opinions, relying upon their own research and knowledge.

***Facility-Level Factors.*** Affordability was key in choosing between the AL and NH sites. Five caregivers with sufficient financial resources or whose recipients had sufficient resources, selected AL care over NH care. At the same time, NH care was chosen by the remaining five caregivers who had no choice but to make use of the reimbursement and benefit options discussed in the previous section and available only through the NH site. Fee affordability was

acknowledged as somewhat of a concern, however, for four of five AL caregivers. Both Cecelia Beech and Dee Waterhouse intimated that their recipients were overspending to reside in their AL MCU settings. Dee admitted that she hoped her 90-year-old father would not outlive his available funds. Reba Chatham weighed her options before deciding to move her husband to the AL MCU and is taking an additional amount of funds from their retirement accounts to cover his expenses. Marsha Balfour is grateful that her stepfather had sufficient income and ability to plan for her mother's future needs since this made AL care an option her mother.

The location of the two sites was very important to nine of ten caregivers. Annette Harrow walks to see her husband each time she visits. Sandra Bailey, who is unable to drive, not only relies on her son, daughter-in-law, and sister for transportation to see her husband, but found it extremely difficult to consider being more than the ten miles away from him that she is from the NH she chose. Pamela Hamm believes having the recipient live close to the caregiver's home or work locations helps the caregiver provide oversight and prevents problems, as well as adds a convenience factor. It is advice she provided professionally to other caregivers making residential LTC selections and advice she followed herself. Only Theo Vance set no restrictions on where he selected care for his wife. He is a 45-mile drive from the NH where she lives. Physical design was more important for him.

The physical design of an MCU was quite important to those caregivers seeking secure boundaries for their recipients, Theo Vance and Sandra Bailey. Jilly Thornton desired a secure boundary for her mother and like Theo found that the larger MCU at this NH site provided the greatest amount of space for wandering when comparing other NH MCU sites. A smaller environment, more easily negotiated became important for Cecelia Beech in choosing a location in Metro Atlanta after meeting with an administrator in her mother's home state before the move.

Cecelia realized that the smaller environment created less stress for her mother to negotiate and better supported her mother's quality of life if everything Janet needed was just steps away. Some caregivers also expressed a desire for privacy, as mentioned in the previous section, and while the AL offered some semi-private units, overall, caregivers sought private units for their recipients, unavailable to NH residents unless all fees associated with the room (roommates' fees) were also paid, and even that was limited by availability of a completely empty unit. The physical plant differences between the AL and NH may have been due in some part to the relative ages of the facilities and the times in which their designs were conceived and built.

Choice according to esthetics, somewhat of a class issue, was much more important to AL caregivers like Allene Ballentine who felt an affinity for the décor of the AL site as it was similar to the home she and her husband had shared. Both she and Reba Chatham felt pleased that their husbands liked their rooms, which related to privacy issues and the physical design as well. Dee Waterhouse's father believed he lived in a hotel, a comparison similarly made by Cecelia Beech who thought of the AL as being "grand hotel style." Pamela Hamm's assessment of the NH site was that it "old," but still served the purpose of providing residential LTC. And finally, obviously a facility's admission and discharge policies, the availability of space, and the presence of an on-site MCU were significant facility-level influences.

Adult day programming available in the AL MCU was an additional facility factor. Based upon availability when the MCU was operating at less than residential capacity, non-resident recipients could attend daily for full day sessions. Allene Ballentine, who took advantage of this feature prior to her husband's move to the AL MCU, relied on the program for daily respite.

*Community-Level Factors.* The AL MCU adult day program is also considered a community-level factor. Adult day programs may be a formal care service more readily available in urban environments, though not in all areas. Having this option available to caregivers like Allene Ballentine, not only provides a source for respite care, but provides an option that may assist caregivers in keeping recipients in the home longer. Publicly-funded reimbursement options at the AL setting were unavailable. Residents paid privately, with the exception of LTC insurance benefits, which essentially were a planned private-pay option. Veterans' benefits admittedly could have been an option, according to one AL administrator, but no move had been made to make those available to AL residents. The NH utilized programs that made care accessible to the widest number of individuals. Eighty-percent of NH residents are Medicaid recipients. Medicare assignment and other options, such as a Qualified Income Trust that three of the study's NH recipients require, helped make the NH a choice that is available to a wider number of people and situations. The federally administered and funded Medicaid program, as well as, state policies on Medicaid eligibility, make nursing home residency an option for half of the care recipients.

Regulations in Georgia dictate that Medicaid reimbursement through Medicaid waiver programs is available only in homes with 24 beds or fewer. The majority of these homes do not have MCUs and none of this size was considered by participants. AL regulations allow facilities to deny admittance and to discharge individuals when behaviors involve unresolved combativeness or are aggressive. None of the recipients choosing AL care had these issues. Some of the NH users, however, did, as in the cases of Annette Harrow's husband, Theo Vance's wife, and Sandra Bailey's husband. Though Jilly Thornton's mother had experienced several psychotic episodes, these were believed to be the result of medication side effects. Jilly's mother

remains sensitive to the influence of medications on her behaviors, but the pharmaceuticals of choice have been amended and she remained stable at the time of the study.

The nature of the communities surrounding the two facilities had some influence of the availability of sites. In the area in which the AL is situated, no NH care is available. The AL community generally is mostly white and affluent and is considered to be a bedroom community of the greater metropolitan Atlanta area. The NH is the only NH in the community in which it is located. The NH's surrounding community, while suburban, is of mixed-use commercial and residential, but is significantly more urban than the community surrounding the AL, with significantly more working class and transient home, apartment, and hotel housing. It is also more racially mixed and ethnically mixed. While more upscale LTC options exist in the general NH area, they are situated within the upscale areas of this suburban setting.

### ***Summary***

Site selection, like many other facets of caregiving, is a complex combination of many factors of multiple levels. Individual-level factors helped set the direction of caregivers' searches for residential LTC with financial resources figuring most significantly among these as it was the main variable driving site decisions among study participants, particularly those moving to NHs. Five of the ten caregivers were relegated to making choices for the NH site because they could not afford AL care and because only NH care is reimbursed through Medicare and Medicaid. But, even AL users had concerns about the fees associated with AL, with some admitting that expenditures were high for their situations.

Second in importance of factors influencing in caregivers' site choices were recipient characteristics. Spousal caregivers especially were knowledgeable about recipients' care needs and were very familiar with the extent of the care required. Encounters with behavioral issues

and heavy ADL needs were instrumental in four of five spousal caregivers initially choosing specialized care in MCUs.

Some caregivers of AL residents voiced preference for AL over NH settings and much of this could be related to class and values. AL users had the ability to exercise choice, where NH users' choices were limited. Seven of ten caregivers either solicited or received advice from trusted sources about the kind of site they chose. Nearly half of caregivers looked for certain types of programming, such as physical therapy, occupational therapy, dementia-specific programming, and activities for their recipients and these were found to exist in both settings.

In terms of facility-level factors, affordability again separated caregivers into AL and NH users, as AL was overall more expensive and exclusively private pay. Nine of ten caregivers chose sites because of the location. Still, physical design was important, but significantly different in the two sites perhaps due to the two facilities' ages. One important feature of each was the secured perimeter of the MCU for residents at risk for elopement. The amount of privacy allowed in the AL setting was of the utmost importance to AL users. Other facility-level factors, such as décor and style, somewhat class issues, were also important to some caregivers.

Finances also figured into community-level factors as publicly-funded reimbursement options were unavailable at the AL site, whereas Medicare, Medicaid, and Qualified Income Trusts were options for NH residents. Regulations further limited four recipients to NH care because of their difficult-to-resolve or aggressive behaviors. The two sites, AL and NH, were located in distinctly different community types and respective surrounding populations, with the AL being found in a predominantly white upscale bedroom community in the outskirts of the greater metropolitan area and the NH in a suburban, but more racially and ethnically

heterogeneous mixed-use community of commercial property with working class and transient housing.

### ***Outcomes of Moving Decisions***

Caregivers' outcomes related to having made the decision to move care recipients out of their homes to a residential LCT setting, revolved primarily around emotions, including feelings toward care recipients, but they also included new coping strategies and lifestyle and role changes. Grief is the chief-reported emotional reaction of seven of ten study caregivers, common to all five spousal caregivers and two non-spousal caregivers. Caregivers reported having feelings of sadness and instances of crying in five of ten situations. Most of these reported outcomes are those of spousal caregivers.

Other, more positive feelings were also reported as being felt as well, the most common being trust, associated with trust of formal care in the LTC settings, reported by four recipients, half of whom are non-spousal caregivers. To a lesser degree, feelings of acceptance, making peace, and thankfulness were noted, with one spousal caregiver expressing all of these and spousal caregivers expressing acceptance and making peace separately. One spousal caregiver voiced thankfulness. Among feelings toward care recipients, a sense of caregiving obligation continues among all caregivers.

Instances of self-awareness were noted by three out of five non-spousal and four out of five spousal caregivers acknowledging that some form of recovery from carework is required. Another most-often reported outcome is having the freedom to live one's life, expressed by four non-spousal caregivers and two spousal caregivers. Caregivers developed a variety of strategies to cope with changes wrought by their caregiving experiences, including exercise, meditation, and reliance on faith practices, support groups, or merely staying busy.

The majority of caregivers reported developing new ways of finding a life beyond the restricted one they experienced as caregivers. All five non-spousal caregivers reported putting an emphasis on other relationships in their lives now, while only one non-spousal caregiver felt this way, likely because they had experienced the least disruption from caregiving. The next most often-reported lifestyle change was engaging in new activities, such as traveling and reading, reported by four caregivers each.

Though their roles have changed, caregivers are still involved with their recipients. Two spousal caregivers assist their recipients daily by feeding them. Advocacy is an important role for four NH caregivers, two of whom are spouses. Possibly advocacy is viewed as of greater importance in the NH setting. Three spouses visit their recipients daily or, in the case of those assisting with feeding, multiple times a day. Another six caregivers visit with their recipients at least weekly or even multiple times a week. Only one caregiver, Dee Waterhouse, visits intermittently.

### *Summary*

The process of decision-making for initial moves to residential LTC was dependent in great part on two significant findings, experiences of caregiver burden and the advantages or limitations of financial resources. Numerous other influences interacted to affect both of these findings.

Caregiver burden was found to be different among the two main types of study participants, spousal and non-spousal caregivers. Spousal caregivers lived with care recipients until their moves to residential LTC, and the nature and values of the marital relationships influenced the level and type of burden they experienced. Among the study's spousal caregivers (four wives and one husband), all were found to be in loving decades-old relationships and each

felt a keen sense of duty in dedicating themselves to the new role of caregiving. Non-spousal caregivers' relationships, on the other hand, had qualities that related to having offspring or sibling relationships to their recipients. All non-spousal caregivers were found to share the experience of renewed negative aspects of family history that served to overshadow their feelings about recipients and the caregiving role. Non-spousal caregivers felt varying degrees of attachment to their recipients from little affinity to greatly conflicted. Unlike spousal caregivers, none of the non-spousal caregivers resided with their recipients.

Real and perceived experiences of burden were further affected by differences in carework, which were substantially different between spousal and non-spousal caregivers. Spousal caregivers' carework centered on providing heavy amounts of ADL care and behavioral supervision, routine medication management, and IADL assistance. Recipient values, such as independence, further influenced their burden by creating more work or making carework more difficult to perform, thereby adding to the emotional burden of caregivers. Various, their work was describing in terms of it being never-ending. The carework of non-spousal caregivers, however, focused on IADL assistance with only one instance of medication management. Reactionary solutions to behavioral problems, rather than proactive solutions were common.

Caregivers were found to receive varying amounts of informal and formal assistance which influenced burden and timing of moves. Informal assistance was found to be provided by family and friends and the nature of it was both instrumental care and emotional support. Finances played an essential role in access for formal care services and had the ability to affect burden in as much as caregivers with sufficient resources were able to reduce or modify burden with the addition of formal care. Caregiver options for moves also affected timing of some moves, as did knowledge of dementia.

Primary decision makers, all primary caregivers, were variously assisted or influenced by others in their decision-making for initial moves, including their own children or other family members, friends, physicians, or other professionals. Physician influence provided the strongest influence in spousal decision-making. Overall, more individuals were involved in spousal decisions than for non-spouses and most of non-spousal support for decisions came from other family members and other professionals.

Site selection, whether for AL or NH locations, fell into two distinct groups, initial moves into MCUs or initial moves into intermediary locations of those sites general care populations. All caregivers were influenced by a host of individual-, facility-, and community-level factors. At the individual-level, personal tastes and values and most importantly, financial resources, steered caregivers toward ALs or NHs, followed closely by recipient characteristics. Class values emerged among most AL residents, particularly those who held privacy and décor as influential factors in selection. Most study caregivers sought or received opinions from trusted sources about the kinds of sites they chose. Many investigated the kinds of programming or commented on the amount of attention available to their recipients.

At the facility-level, affordability again was key as the AL offered no reimbursement financial benefit options and the NH offered several, including acceptance of Medicare, Medicaid, and use of Qualified Income Trusts. Site location was also very important to almost all caregivers in being able to maintain close contact with their recipients or as a convenience factor in their own lives. Physical design was quite important to caregivers seeking secure boundaries for recipients in both the AL and NH location.

Community-level factors supplied additional influences as each site was situated in different types of communities. No NH care was available in the area of the AL which was

primarily an affluent bedroom community. AL regulations also had some influence on AL versus NH choice.

## CHAPTER 7

### CONCLUSION

The overall purpose of this study was to better understand decision-making processes of primary informal caregivers for their recipients' moves to memory care. The study provides an in-depth qualitative examination of experiences recounted by ten primary informal caregivers in guided recorded interviews whose recipients now reside in MCUs, five in an AL MCU and five in a NH MCU. Primarily, the study addresses factors influencing how these decisions were made by investigating who was involved in the process, learning these individuals' various viewpoints and when decisions were made, as well as what locations were considered and ultimately, why decisions were made for specialized memory care as a residential LTC option. A multi-level examination of these questions by individual-, facility, and community-levels provided deeper insight of important and relevant factors. Decisions for moves were found primarily to be influenced by one key factor: varying aspects of caregiver burden. Caregiver burden then is influenced by multiple interactive factors, primarily at the individual level. The level of financial resources of care recipients and caregivers also was a key influence, both directly on the timing and options for moving and indirectly through burden, either providing or limiting opportunities for obtaining formal care services. The following sections discuss findings of the data, linking them to earlier research, and notes policy and practice implications, study limitations, and suggestions for future research.

#### *Discussion*

According to the literature, a strong association exists between dementia caregiving careers and familial obligations for risk of change to personal stability in four main areas including psychological and physical well-being, social interaction, and financial well-being

(Aneshensel, 1995). Findings from the current study support these previous findings. The study's participants sought residential LTC solutions for their recipients outside the home setting because of their caregiving experiences and responses. Experiences varied greatly according to the types and number of care tasks performed, including providing for ADL and IADL needs, supervising recipient behaviors, and managing medications and safety. Caregiver responses to these tasks resulted in physical, emotional, and/or social stress. The type of caregiver to recipient relationship was important to how the stress response developed and from what carework activities it was generated. Researchers have noted that such burden experiences, emanating from dementia carework, may lead caregivers to seek formal LTC solutions (Aneshensel, et al., 1995; Armstrong, 2000; Gaugler, et al, 2005; Gaugler & Tester, 2006; Gwyther, 1998; Spitznagel, et al., 2006) Savundranayagam and colleagues (2011) study reports a similarly complex experience of burden among spousal and grown offspring caregivers of chronically-ill recipients. Ball and associates (2009) refer to the accumulating needs of recipients resulting in decisions for moves as "push factors," noting that care recipients' growing deficits may interfere with their abilities to remain in the home setting (p. 101).

The literature explains that carework experiences of informal caregivers of recipients with a dementia are complex, vary greatly, and cause significant impact, identifying them as "caregiver burden" (Aneshensel, et al., 1995; Croog, et al, 2006; Dang, et al, 2008; Spitznagle, et., 2009, Zarit, 2008, p. 101). Similarly, the study's participants, all caregivers of individuals with varying dementia diagnoses, engaged in numerous care activities according to their own situations, internalizing their experiences relative to their individual perspectives and relationships, resulting in deeply personal and complicated outcomes of burden. Altogether, the wide array of tasks they reported variously consisted, in some part or wholly, of attending to

ADL deficits, such as bathing and grooming, toileting or incontinent care, and feeding. Other care tasks associated with IADL needs included financial oversight, transportation, and meal preparation, along with carework such as medication management and monitoring of behaviors such as wandering, combativeness, or hallucinations, among others. As a result of their carework, consisting of any number of these tasks, all study caregivers reported accumulating some measure of physical and psychological difficulty including complaints of lost sleep and exhaustion, poor eating habits, changes to physical health ranging from minor illnesses and infections to serious concerns such as heart conditions, as well as emotional reactions, such as anger, crying, frustration, grief, resentment, worry, and depression.

At the same time, it is important to acknowledge not only the emotional reactions of the study caregivers, but the different ways in which those reactions had been resolved at the time the current study was conducted. Bonanno (2009) has explored the topic of “bereavement” and found that the capacity for resilience in the face of grief can have a modifying effect on its resolution (pp. 6-8). He also notes that the varying emotions experienced in reaction to situations serve a purpose by helping individuals “manage” and process their “challenges” (p. 29). Feelings, such as “sadness, become essential tools” that promote acceptance and accommodation of losses felt “during bereavement” (p. 31). Among study caregivers, feelings associated with grief and loss were processed and resolved over varying periods of time. Some caregivers whose recipients had been placed for approximately the same length of time acknowledged acceptance of their recipients’ further declines and subsequent institutionalizations much sooner than others. Other caregivers reported experiencing continued and great emotional difficulty adapting to their recipients’ declines and placements.

In the present study, spousal caregivers had a different form of adaptation to make when resolving feelings about their absentee recipient spouses. Kaplan (2001) noted typologies among couples in which one spouse with Alzheimer's disease had been placed in an institution. One typology, that of the "Husbandless Wives/Wifeless Husbands" described three unique sets of feelings about their situations: "being 'in limbo,'" acknowledging "a distinction between being married and feeling married," and "thinking more of themselves in their day-to-day lives" (Kaplan, 2001, p. 93). Findings among spousal caregivers in the present study are consistent with these typologies as they sought to create new spousal roles in their marriages.

In regard to physical changes that may be experienced by caregivers of persons with a dementia, Von Kanel and colleagues (2008) found that caregivers of individuals with a dementia have a higher associated risk of coronary heart disease and more depressive symptoms according to findings from the Framingham Coronary Heart Disease Risk Score. Other researchers, as well, have suggested that the physical component of dementia caregiving results in caregiver "stressors" experienced both psychologically and physically (Aneshensel, et al, 1995; Dang, et al., 2008; Papastavrou, et al, 2007; Zarit, 2008, p. 101). Another study noted a comparable response of caregiver burden among both spousal and offspring caregivers resulting from the physical burden of ADL carework (Savudranayagam, Montgomery, & Koloski, 2011). They also reported that in regard to behavioral supervision, spouses and offspring had similar responses of burden to dementia carework, resulting in increased physical burden effects, related stressful response, and experiences of "relationship burden" (Savudranayagam, Montgomery, & Kosloski, 2011, p. 326).

The present study includes five spousal caregivers, four offspring caregivers, and one sibling caregiver. In this diverse group two patterns of experience emerged, that of spousal and

non-spousal caregiver, dissimilar because of caregiver to recipient relationship type, and by extension, caregiver and recipient history together. Living arrangements were different as well, as none of the non-spousal caregivers lived with their recipients. A reflection of these very basic differences between the two groups is found in how their caregiver burden emerged and was experienced. Ball and associates (2005) speak to the variety of relationships in families, the caregiving configurations found among them, and the impacts caregiving have on those involved. Referring to “continuity” they note that relationship “patterns” established prior to the onset of caregiving are likely to continue once caregiving ensues (Ball, et al., 2005, pp. 149-150). Similarly, relationship burden responses experienced by this study’s spousal and non-spousal caregivers also were found to be of like impact though they presented differently.

Caregivers’ role changes also influenced burden. Adams (2006) notes that some psychological and emotional experiences of burden are associated with relationship role changes. For four of five spousal caregivers, marital role change was a major finding that produced attitudinal changes toward their recipients that were particularly poignant as spousal caregivers compared their spouses’ diminished abilities to qualities of children with requirements of assistance and supervision. Marital relationships among the study’s spousal caregivers were very similar in terms of closeness and sense of duty associated with caregiving. However, not all marital relationships may be as positive and not all spousal caregivers may be as devoted as those of the study’s participants. Societal change such as increased divorce, along with changing gender roles, has the potential to affect future caregivers even more.

Caregiver stress also has been found to evolve when dementia caregiving opens old conflicts within the family network renewing negative experiences of “unresolved feelings and conflicts” (Kane, et al., 2007, p. 247). A major finding among the study’s five non-spousal

caregivers was that all five experienced varying, but strong degrees of tension and difficulty related to issues of unresolved family issues relative to dementia carework. The problems of “family conflict” can be significant (Aneshensel, et al., 1995, p. 85). According to researchers, “family members must adapt to the new persona and behaviors of the dementia patient under the backdrop of the family’s history and the biographies of its members” (Aneshensel, et al, 1995, p. 85).

In an effort to reduce stress associated conflict experienced between caregiving roles and personal lives, some study caregivers made lifestyle changes. Aneshensel and colleagues (1995) have noted that dementia caregiving can become overwhelming and intrusive in unrelated areas of caregivers’ lives causing caregivers to seek solutions that are not wholly positive, such as retreating from social contact. Study caregivers reported two types of such changes. Three spousal caregivers, two wives and one husband, quit paid employment to focus solely on their recipients. Spousal caregivers also gave up regular activities and curtailed their social lives. Non-spousal caregivers, on the hand, whose direct caregiving activities were much less intense compared to spousal caregivers, found their lives much less affected.

Recipient characteristics associated with dementia behaviors have been noted to elicit the most robust caregiver responses to carework, surpassing those linked with cognition (Croog, et al., 2006; Eters, et al., 2008; Papatavrou, et al., 2007). A related study found that stress associated with ADL carework for chronically ill recipients significantly impacts spousal caregiver decisions for institutionalization while “relationship burden” significantly impacts decisions for offspring caregivers (Savundranayagam, et al., 2011, p. 326). Nine of ten participant caregivers, in the current study, related instances or concern related to dementia behavioral issues, primarily wandering, but also aggression, combativeness, hallucinations, and

mania or prolonged periods without sleeping. Dementia behavioral problems were an influential reason for seeking residential LTC, second to providing ADL care among study participants. For two spousal participants dementia behavioral problems or specific risks of wandering led them to initially select MCU placement. But, for an additional three other recipients, two non-spousal and one spousal, it was the main reason why they were transferred from the general population area to the MCU setting.

A finding among a small number of study caregivers related to decisions to move, particularly for initial moves to the MCU setting, was the influence of the knowledge of dementia. Two spousal caregivers made decisions to move their recipients in part because of self-study about their recipients' dementia conditions and an acquired understanding of aspects of anticipated declines from AD and LBD. Several caregivers admitted to acquiring knowledge from physicians and other professionals about their recipients' dementia conditions and outlooks. This, along with reinforcement from professionals, friends, and relatives emphasizing how over time they would not be able to continue in the dementia caregiving role due to both recipient characteristics and accumulating burden, influenced caregivers' decisions for moves.

Researchers from one study of caregivers of individuals with a dementia, noted greater reception to residential LTC solutions based on the influence of knowledge of dementia (Spitznagel, et al., 2006). They surmised that the acquisition of dementia knowledge enabled caregivers to more fully grasp the deficits and problems of later dementia including cognition and potential behavioral problems that they might face as caregivers (Spitznagel, al., 2006).

Another finding of this study relates to finances. Aneshensel (1995) has noted that caregivers may face considerable stress from both the costs of providing care and the loss of earned wages. A second study showed that finances, along with other elements, impact decision-

making not only for moves to residential LTC, but facility types, the “timing” of those decisions, and other “living and care arrangements preceding” move decisions (Ball, 2009, p. 104). Ball and associates (2009) also note that while “push factors” of “increasing disability” may be a reason for seeking residential LTC, “pull factors” are related to wider ability to choose among types of solutions, including residential LTC settings (pp. 101-102). In the present study, level of financial resources restricted five caregivers’ decisions to choosing the NH site for their recipients, while it enabled the remaining five caregivers to choose the AL site. Still, two of the five caregivers choosing the AL site expressed some concern about continued affordability, while two others acknowledged the expense and how their particular situation made the arrangement possible. Ball and colleagues (2005 and 2009) have found that having the option for desirable AL care may make the move occur sooner.

Accessibility to financial resources also limited or enabled study caregivers in their use of formal supports, potentially influencing experiences of increased or decreased burden. Zarit (2008) found that caregiver use of interventions and strategies such as use of brief or long-term formal care options reduced stress responses.

Caregiving values in society have been noted as being influenced by issues of race, gender, and culture (Dilworth-Anderson, Gibson, & Burke, 2006). Dilworth-Anderson and colleagues note that caregiving “within most ethno-racial groups in the United States” is administered by offspring, more so than among both “Hispanic” and “European American families” (pp. 128-129). “Carework” is also found to be more prevalent among “women [who] comprise more than three-fourths of informal carers of the old” (Calasanti & Slevin, 2001, p. 146). This has been noted to hold true for caregivers of every race and ethnicity, with the exception of Asian caregivers in which females and males are represented nearly evenly

(Calasanti & Slevin, 2001). Among male and female spousal caregivers who have been found to take on the gender-associated former tasks of their recipients, their “gendered life courses” not only affect what kind of carework they assume, but the difficulty with which they experience or frame their new cross-gendered tasks (Calasanti, & Bowen, 2006, p. 257; Calasanti, & King, 2007). Women, it’s noted however, have more experience with personal care tasks as an extension of their gender roles (Calasanti, & Bowen, 2006, Calasanti, & King, 2007). Even so, Calasanti and Bowen (2006) found that “caregiving husbands” were similar to caregiving wives when it came to attention to detail for grooming tasks (p. 259). In the current study, wives and the sole male caregiver each took on cross-gendered personal care tasks, seeking to preserve the gendered identities of their spouses, including providing them with personal grooming and attention to dress. Home tasks typically handled by their recipient spouses, such as managing finances, tackling home repairs and maintenance or making decisions about these, or cooking, shopping, and cleaning were other types of gendered tasks that were adopted.

In a study seeking to understand the “role of religion and ethnicity” in providing care for elders with a dementia, Levkoff and colleagues (1999) found “an ethnically-based sense of obligation to care for their” recipients within the family setting (p. 350). Winslow and Flaskerud (2009) agreed, noting instances of obligation to care for family elders among ethnic minority participants in their study on LTC placement. A similar effect may have been an influence in the care situation of the sole Caribbean Black recipient in the present study, whose two children provided homes for him and their mother before his eventual move to a formal residential LTC situation.

Choice of residential LTC, whether limited or supported by financial resources, differed among study caregivers according to initial choices for MCUs or intermediary choices for

general population AL or NH settings. One study noting move decisions found that they differed among spouses and offspring, with spouses' decisions being strongly linked to "increased burden" (Kelsey, et al., 2010, p. 258). Offspring on the other hand, reported move decisions being related to recipients' lack of self care or "sudden crisis" (Kelsey, et al., 2010, p. 258) Four spousal caregivers made initial decisions for MCUs, two in the AL and two in the NH. Initial moves by spouses to the MCU may in part reflect their greater commitment to caregiving longer and therefore accumulating greater burden due to their recipients' increasing disabilities or "push factors" (Ball et al., 2009).

For the participants who had intermediary moves to the general populations of either the AL or NH, in all cases facility administrators were the primary decision-makers regarding moves to the MCU. Two studies noted that administrator interventions for resident transfers from the general AL population to the MCU setting are triggered by several issues including, "wandering" and behaviors, and increasing ADL needs (Kelsey, et al., 2008; Kelsey, et al., 2009, pp. 196-197). Of the three study caregivers whose AL recipients encountered transfers to MCU settings, ADL care and wandering figured prominently. In regard to NH residents, Wacker and Roberto (2008) found that dementia-associated behaviors are prominent characteristics among those in NH MCUs. Recipients of three of the present study's caregivers who chose NH general population settings, all were transferred to the MCU setting because of administrative decisions due to incidents of elopement.

Recipients in the present study, it should be noted, did not participate in decisions for their institutionalization. Menne and Whitlatch (2007) have found that among individuals with a dementia being cared for by relatives, "increased cognitive and physical impairment often comes [with] decreased decision-making involvement" (p. 817). Additionally, factors such as recipient

needs associated with ADLs and indications of depression were strong indicators “and significant predictors” of how involved recipients were able to be in making decisions for their own care (Menne and Whitlatch, 2007). None of the recipients, at the times of their moves, were reported able to participate in move decisions due to their greatly reduced cognitive capacities and heavy needs for care. These findings are consistent with other AL research that shows that elders have little involvement in moving decisions (Ball et al., 2005, 2009).

### *Policy and Practice Implications*

As the number of individuals with dementia diagnoses increases, and with it the number of caregivers, many sectors of society will be impacted. Dementia caregivers are a heterogeneous group, in as much as factors of differences of employment, need and use of publicly-funded reimbursement programs, age and generation, as well as many others, related to gender, race, class, and culture. Business, in both employer and employee aspects, healthcare systems, family services, and formal LTC providers of all types from agency to facility, will need to address the needs of a widely varying group of individuals and resource users. How individuals and families meet their obligations must correspond with how entities such as business, healthcare, government, private and public agencies and others perform and serve. New policy should not restrict the abilities of these different entities to thrive, but should encourage adaptation to meet increased demand for services in a manner that supports the economic health of all principals involved. Current reimbursement policies in residential LTC are weighted toward NH care rather than a wider encompassing set of options such as AL, including MCUs, limiting options for informal dementia caregivers who are making decisions for their recipients’ moves. For workers in LTC settings, knowledge about dementia and contemporary care approaches are essential. Administrators, supervisors, and those who assist

families in care planning as well as those who implement care will benefit from increased knowledge of both. Training curricula and credentialing criteria, as well as licensing requirements should reflect basic and up-to-date knowledge of dementia and contemporary care approaches.

Practice implications are many as well. Systems and procedures that support caregivers and recipients in the home and community where they reside are vastly important. Those that allow recipients to safely remain in their homes and communities longer are among the most important. A critical component of recipient care is caregiver support and respite. Community programs that help caregivers learn useful care practices and contemporary relational approaches, while assisting them to understand the characteristics of their recipient's type of dementia, will aide caregivers in moving beyond intuitive approaches in their carework to the practical application of techniques that increase safety and communication in daily care, and may have the additional benefit of reducing caregiver stress. Initiatives and programs that provide respite for caregivers, positively support the personhood of both caregivers and recipients, in educational, recreational, instrumental assistance will add to quality of life for caregivers, recipients, and significant others who are intimately involved in the family situation. Suggestions include increasing the number of adult day services and respite outlets and expanding home services, home maintenance, and modification projects to increase both safety and quality of life for both caregiver and recipient, with particular attention paid to geographically isolated areas where public services are generally in little to no availability. In addition, coordinating community needs with the full cooperation of community resources, such as private and non-profit entities to work alone or in partnership with public entities, will be essential to effect these changes.

### *Study Limitations and Strengths*

The present study design of ten caregivers was limited in scope impacting relevance of the findings to a broader number of caregivers with of those with dementia diagnoses. The study's caregiver participants included a disproportionate number of spouses and daughters relative to other types of caregivers of differing familial relations. In addition, the five spouses were weighted toward wives not allowing for differences that might occur among husbands who take on dementia caregiving. The only male spouse was also the only male participant in the study, further limiting gender perspectives. The spousal caregivers' similar type of marital relationships with their spouses also neatly aligned with one another, creating much more similarity than difference, further limiting a broader scope of findings. Among caregivers with more significant assistance from one or more family members, perspectives of those providing secondary assistance were not included and some nuances were missed in these situations. One other limitation is that other caregiving relationship types, such as guardianships, were not included in this study.

In addition to gender inequality, little information was available in regard to race as nine of ten caregivers were white. Though some elements of class and culture emerged from the findings, they were limited by the number of study participants and the type of questions asked during guided interviews.

Study sites were limited as well. Participants at only two facilities were considered. Other types of facilities offer specialized memory care in secure settings. Though CCRCs and stand-alone MCUs exist in the greater metropolitan Atlanta area, none were included. A greater understanding of MCU admissions, as well as transfers, could be obtained by including these other types of settings. More representative findings of caregiver decision-making experiences

could be obtained from additional facilities in different types of communities and locales and of different sizes, further capturing aspects of race, class, and culture that are missing.

### ***Future Research***

As the growing presence of dementia is a pressing societal concern for individuals, families, as well as healthcare and LTC entities and providers, among others, future research that addresses the study's topic in more depth is important. Obtaining more extensive information and perspectives from caregivers and the variety of professionals with which they interact, including healthcare and formal care services, could provide additional insights into the decision-making process. Perspectives could include caregiver follow-up at some future time after moves have occurred, as well as, professional perspectives of hospital discharge planners, facility administrators, care agency operators and others who make assessments for admission or transfer to MCUs. Understanding caregiver insights as they relate to dementia would assist professionals working with families leading up to and during transition points, times that can be fraught with high and multiple levels of emotion and understanding.

Studies of broader scope and increased participant and site numbers would create a greater potential for obtaining findings expressing viewpoints of multiple ethnicities, ages and generations, differing classes and cultures, as well as more gendered experiences. Multiple types of sites and in different locales would further expand findings. Other study suggestions include investigating dementia knowledge and application of that knowledge through care approaches by two main groups, formal care agency facility professionals and informal care providers. These types of studies should seek to learning more about what dementia knowledge is obtained, how it is acquired, and the age and validity of what is known and believed by all parties.

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**APPENDIX A**

MCU Code: \_\_\_\_\_ Participant Code: \_\_\_\_\_ Date: \_\_\_\_\_

Interview Start Time: \_\_\_\_\_ AM PM Interview End Time: \_\_\_\_\_ AM PM

I am interviewing key family caregivers of persons with a diagnosed dementia who now reside in memory care in the metropolitan Atlanta area. My main goal is to learn how decisions are made for moves to memory care and what affects how those decisions are made. I am interested in the lives you and your family member with a dementia led prior to the dementia diagnosis, the changes that you experienced in your lives and relationships as a result of the developing dementia, interactions with professionals, how you are doing today, and what things affected how the decision was made for the move into memory care.

Before we start the interview, I want to give you a letter that explains the study, your rights as a participant, and what you might expect. Part of this explanation assures you that what you share with me is confidential. Your name and the name of your family members, as well as the name of the memory care facility, will not be made public. Should you choose to participate, I have a consent form that we will both sign and date. A copy of this consent form will be yours to keep.

Because what you have to share is important, I want to be sure to remember every detail. With your permission, I will record our conversation.

**Georgia State University  
Gerontology Institute**

## **1 Informed Consent**

**Title:** Decision-Making Processes of Primary Informal Caregivers  
Regarding Care Recipients' Moves to Memory Care

**Principal Investigator:** Mary M. Ball, Faculty Advisor and Primary Investigator  
Vicki J. Stanley, Student Primary Investigator

### **I. Purpose:**

You are invited to take part in a research study. We want to learn how decisions are made for moves to memory care and what affects how those decisions are made. Memory care is a place where people with memory problems sometimes live to be cared for by others. Dementia is one word used to describe memory problems and problems making decisions, and changes in behaviors, speech and language, or mental and physical abilities. You are invited to join the study because you are a key family caregiver of a person with a dementia who now lives in memory care. In all, 20 total people from two different study locations will take part in this study. The study will take about one and one-half hours of your time.

### **II. Procedures:**

If you agree to be in this study, you will allow Vicki J. Stanley to interview you at a time and place you choose. The interview will be like a conversation. It will last about 1 ½ hours. It will probably take just one session. With your okay, it will be audio recorded. Some questions will be about you and your family member who has memory problems. Some questions will be about other family members and professionals who helped you. Other questions will ask what it was like to be a caregiver. We want to learn how you are doing today so that we can know more about things that affected how the decision was made for your family member to move into memory care.

### **III. Risks:**

In this study it is possible that you might feel some emotional upset. If you feel uneasy, you may skip questions or stop the interview at any time. If you become emotionally upset, you may ask to be referred to a qualified mental health provider.

### **IV. Benefits:**

Being in this study will not likely benefit you personally except to give you time to talk about what it has been like to be a caregiver. Overall, we hope to learn how key family caregivers make decisions for family members' moves to memory care. What you tell us may help professionals

know how to help make life better for other family caregivers going through the same thing.

V. Voluntary Participation and Withdrawal:

It is your choice to join this study. You do not have to be in this study. If you decide to be in the study and change your mind, you have the right to drop out at any time. You may skip questions or stop taking part in the study at any time. Whatever you decide to do will not affect how you or your family member will be treated.

VI. Confidentiality:

We will keep your records private to the extent allowed by law. Dr. Mary M. Ball and Vicki J. Stanley will have access to the information you give. Information may also be shared with those who make sure the study is done correctly (GSU Institutional Review Board, the Office for Human Research Protection (OHRP)). We will use an identification number code instead of your name on study records. The information you give will be stored in a locked cabinet and in password-protected computers. A key to coded information will be stored separate from the data to protect privacy. The key will be destroyed after the information we collect has been studied. Typed transcripts of the audio recordings will be made and the recordings will be erased. Typed transcripts will contain no identifying names of people and places. Your name and other facts that might point to you will not appear when we present this study or publish its results. The findings will be summarized and reported in group form. You, your family, and the facility will not be identified personally.

VII. Contact Persons:

Contact Dr. Mary M. Ball and Vicki J. Stanley if you have questions about this study. If you have questions or concerns about your rights as a participant in this research study, you may contact the Office of Research Integrity.

VIII. Copy of Consent Form to Subject:

We will give you a copy of this consent form to keep.

If you agree to be in this study and be audio recorded, please sign below.

\_\_\_\_\_  
Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Principal Investigator or Researcher Obtaining Consent

\_\_\_\_\_  
Date

## APPENDIX B

### DEMOGRAPHIC QUESTIONS

**I'd like to begin by asking a few brief questions about you and your family member who has a dementia. (Name of individual substituted where CR appears, as able or appropriate.)**

1. What is your relation to your care-recipient? \_\_\_\_\_  
(spouse, offspring, other family relation- name type)
  
2. Could you tell me your age? A. Age of caregiver \_\_\_\_\_  
 Could you tell me the age of (CR)? B. Age of care recipient \_\_\_\_\_
  
3. (Observe) A. Gender of caregiver \_\_\_\_\_  
 (Provided with answer to #1) B. Gender of care recipient \_\_\_\_\_
  
4. What do you consider to be your race? A. Race of caregiver \_\_\_\_\_  
 What do you consider to be (CR)'s race? B. Race of care recipient \_\_\_\_\_
  
5. How many years did you attend school? A. Caregiver yrs. education \_\_\_\_\_  
 How many years did (CR) attend school? B. Care recipient yrs. education \_\_\_\_\_
  
6. How long have you and (CR) known each other? \_\_\_\_\_
  
7. Could you tell me your legal relationship to (CR)? \_\_\_\_\_  
 (power-of-attorney[POA] for healthcare or finances, legal guardian, none)  
*If caregiver is POA or legal guardian, then #8; if neither, then #9:*
  
8. How long have you been a (POA or legal guardian)? \_\_\_\_\_
  
9. Could you tell me what diagnosis (CR) has been given? \_\_\_\_\_
  
10. Approximately when was the diagnosis given? \_\_\_\_\_
  
11. How long has (CR) lived at the present location? \_\_\_\_\_

12. Has (CR) ever lived in any other memory care units (MCUs)? \_\_\_\_\_

*If no, skip #13 and #14, and proceed to #15.*

13. In how many other memory care units (MCUs) did (CR) live *prior* to moving to the present location? \_\_\_\_\_

14. Altogether, what is the total length of time (CR) lived in other MCU(s)? \_\_\_\_\_

15. Has (CR) ever lived in any type of non- memory care facility? \_\_\_\_\_  
( *assisted living [AL], nursing home [NH], other*)

*If no, skip #16 and #17, and proceed to 18.*

16. In what type of non-memory care facility did (CR) live? \_\_\_\_\_  
(*AL, NH, other*)

17. What is the total time (CR) lived in other non-memory care facilities? \_\_\_\_\_

18. Has (CR) ever lived with any other family members or in any other home residence since developing the dementia? \_\_\_\_\_

*If yes, answer #19 or #20 as appropriate.*

19. Altogether, what is the total length of time (CR) lived with another family member? \_\_\_\_\_

20. Altogether, what is the total length of time (CR) lived in another home residence? \_\_\_\_\_

## APPENDIX C

### GUIDED INTERVIEW

#### **PERSONAL HISTORY OF CAREGIVER**

*These questions provide insights about the caregiver, explore relationships and connections between caregiver and family, examine the scope of the caregiver's social network, and probe for the caregiver's caregiving history.*

#### **Could you tell me a little about yourself?**

Probe for: Where born/reared/how came to live in Metro Atlanta

Brief description of family of origin – parents, siblings, and extended family

Brief description of family life, growing up,

Description of closeness or distance in family relationships

#### **What kind of interests do you have and what kinds of activities do you enjoy?**

Probe for: Membership in organizations, clubs, faith communities & hobbies, work

Time spent in interests and activities

#### **Please tell me about your own family.**

Probe for: Instances of marriage, divorce, and widowhood

Children and step-children

Extended family or others living in the home

Previous/current family caregiving responsibilities had inside/outside the home

#### **PERSONAL HISTORY OF CR**

*These questions provide insights about the CR, explore relationships and connections between the CR and family, describe the nature of the CR's social network, and probe for any caregiving history of the CR for others.*

#### **Could you tell me a little about (CR)?**

Probe for: Where born/reared/how came to live in Metro Atlanta

Brief description of family – parents, siblings, and extended family

Brief description of family life, growing up

Description of closeness or distance in family relationships

Instances of (CR)'s marriages, divorces, widowhood

Children and step-children

Extended family or others living in home of (CR)

Previous family caregiving responsibilities (CR) had inside/outside the home

**I'd like to learn a little about the kind of interests (CR) has had over the years.**

Probe for: Membership in organizations, clubs, faith communities & hobbies, work,  
education

**What kinds of things interest (PWD) now?**

### **CAREGIVER/CARE RECIPIENT RELATIONSHIP**

*These questions explore aspects of the type and nature of the relationship between the caregiver and the (CR) and how these may have remained the same or changed over time.*

**Could you tell me a little bit about what your relationship with (CR) was like before any changes began to occur?**

Probe for: Sense of closeness or strain in relationship

Similarities and differences

Types/description of activities enjoyed together throughout relationship

Important life/relationship events shared

Dreams and/or long-term plans of caregiver and (CR) shared

**Could you tell me a little about any differences that have occurred in your relationship with (CR) over time as you came to be (CR)'s caregiver?**

Probe for: How caregiver and (CR) relate one to the other...romance...role reversal

Changes in caregiver's personal responsibilities...what changes

Changes in (CR) personal responsibilities...what changes

### **DEMENTIA HISTORY**

*These questions explore changes and reactions to them, including stressors, that may have impacted the decision-making process related to the move to memory care.*

**Please tell me a little bit about realizing that something changing or different for (CR).**

Probe for: Feeling, inner voice, comments from others (including healthcare professionals),  
and/or problems that might have led to this awareness

**In what way(s) was (CR) changing or different?**

Probe for: (CR) personality, behavior, memory, habits

**What health concerns, if any, were being experienced by (CR) at this same time?**

*(Foundation for follow-up question on page 9 regarding influence of (CR)'s health on the decision for memory care.)*

**How did your role as (CR)'s caregiver begin to develop?**

Probe for: Formality or informality of relationship... How responsibility was assumed  
Sense of obligation, if so, how so...Feelings about responsibilities

**Could you tell me about what a typical day was like for you and (CR) after you began caregiving?**

Probe for: Types of assistance caregiver provided...When assistance occurred...How often assistance occurred...Duration of assistance over time...In what ways assistance may have changed over time and why it changed

**How did you feel about the types of assistance you provided (CR)?**

**Could you tell me about any changes *you* may have experienced or undergone over time as a caregiver?**

Probe for: General health...eating...sleeping...depression  
Substance use...self-medicating...OTC, alcohol, other? Prescription?

Disruption of routine...home responsibilities...work responsibilities...free time

Economic disruption...income...disposable income...mounting bills

Social interactions...canceling or dropping out of activities...changes in others toward self or (CR)

**What unpaid assistance from others did you receive before (CR)'s move to memory care?**

Probe for: Assistance from family, friends, others

**Could you tell me a little about any formal or paid care services that were used before (CR)'s move to memory care?**

Probe for: Which services were used including respite care (in/out of home)...adult day services...caregivers or home aides

**If formal services used: How did you find out about (type[s] of care services used)?**

**How did you decide to use (type[s] of care services)?**

**If no formal services were used: Could you tell me a little bit about the reasons why formal or paid care services were not used?**

**You've told me about several different experiences you had as a caregiver. What effect did these experiences have on the decision for the move to memory care?**

Probe for: Stressors related to personal physical and mental health... carework... relationships...competing responsibilities...finances...social interactions

**DEMENTIA KNOWLEDGE**

*This section explores the caregiver's knowledge of and experiences with dementia prior to and after diagnosis, and how acquiring knowledge about dementia may have influenced the decision-making process of a move to memory care.*

**Prior to (CR)'s diagnosis, what did you know about dementia?**

Probe for: Concepts, facts, misconceptions

**How did you come to learn these things?**

Probe for sources:    Self-discovery...media...word of mouth...print material...website  
                               Professional...healthcare...social worker...case manager...administrator  
                               Faith leader or faith community  
                               Dementia advocacy program(s) or organizations  
                               Family/acquaintance experiences

**Prior to (CR)'s diagnosis, did you know of or interact with others with a dementia? How?**

**Could you tell me a little of what you know about (CR)'s type of diagnosis?**

Probe for:    What understanding caregiver has about (CR)'s type of dementia

**What type of professional provided this diagnosis?**

**When you learned of the diagnosis, what information were you given about it?**

Probe for:    Oral...printed...referral(s) to other professionals  
                               Who provided this information

**What effect did your general knowledge of dementia have on the decision for the move to memory care?**

Probe for:    Consulting others (who?)...planning (how?)...lifestyle/carework changes (what?)  
                               Emotional impact...concerns for (CR)'s future...change to/loss of relationship

**How did learning about (CR)'s diagnosis influence the decision for the move to memory care?**

Probe for:    Consulting others (who?)...planning (how?)...lifestyle/carework changes (what?)  
                               Emotional impact...concerns for (CR)'s future...change to/loss of relationship

### **THE DECISION TO MOVE TO MEMORY CARE**

*These questions explore issues and events related to making the decision for a move to memory care and the people involved with the decision-making process.*

#### **How did the *idea* for making the move to memory care come about?**

Probe for:     Factors related to caregiver...stress...health...finances...personal freedom  
                   Factors related to (CR)...health...behaviors...care issues...escalating change  
                   Factors related to outside influence...family...professionals...friends...faith

#### **Could you describe the steps that were taken in the decision-making process?**

Probe for:     Consultations...timeframe...site visits...criteria important to decision-making  
                   Who initiated the discussion...who took part in discussion

#### **What role did (CR) have in *discussions* for the move to memory care?**

#### **What role did (CR) have in *the decision* for the move to memory care?**

#### **What reaction did (CR) have to the decision-making process?**

#### **What person or persons had the strongest influence upon the decision-making process?**

Probe for sources:     Caregiver...(CR)...family...professionals...faith leaders...others

#### **What issue or issues had the strongest influence upon the decision-making process?**

#### ***If applicable:***

**You mentioned earlier that (CR) had a few health concerns, what influence did these have upon the decision-making process?**

#### **Could you tell me what other kinds of things were going on at the same time?**

Probe for issues related to:     Family/home life...work...opportunities/conflicts, other

#### **How did you decide for memory care in (*an assisted living facility [ALF] OR a nursing home [NH]*)?**

Probe for:     Factors important to choice of this type of residential care (also see probes below)

#### **How did you choose this particular (ALF or NH) location?**

Probe for: Geographic location...availability...setting...staff...finances...encouragement or  
Reference from others...prior knowledge of location

**Thinking back on the decision-making process, what if anything would you change about that experience? What would you do differently?**

### **OPPORTUNITY FOR CAREGIVER TO ADVISE**

*These questions allow the caregiver to make suggestions for others based upon their experiences.*

**What advice would you give to other caregivers just beginning to care for someone with a dementia?**

Probe for: What caregiver would do differently...access formal care services?  
What signs and symptoms should be paid attention to in a (CR), in themselves  
Most helpful resources

**What do caregivers need to know about taking care of persons with a dementia?**

Probe for issues related to

Cognitive...physical...mental...safety...legal...financial...lifestyle...family...faith

**What do caregivers need to know about taking care of themselves?**

Probe for issues related to:

Cognitive...physical...mental...safety...legal...financial...lifestyle...family...faith

**What is important to remember about the person (CR) is, separate from (her/his) dementia?**

Probe for: How caregiver views the person, rather than the dementia

**CLOSING QUESTIONS**

**We have talked about many things today. Before we finish is there anything else you'd like me to know about making the decision for the move to memory care?**

**If I later have a question about something that we've talked about today or if I have an additional question about your experience may I contact you at a later date?**

***(If consented)* How would you prefer to be contacted?**